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ABSTRACT

This report on the Intermediate Care Facility for the Mentally Retarded (ICF-MR) and related programs under Title XIX (Medicaid) of the Social Security Act aims to assist in consideration of improvements to Medicaid services. The report begins with a background description of the key Medicaid programs of interest, discussing: federal involvement in care for individuals with mental retardation prior to ICF-MR; establishment of the ICF-MR program; federal "look behinds" of state program review efforts; the phase down option; Medicaid waiver; nursing home restrictions; and proposals for Title XIX reform. The second part contains state-by-state and national statistics on ICF-MR and related Medicaid home and community based services and nursing home utilization. The third part describes characteristics of ICF-MR facilities and their residents, with comparative statistics for noncertified facilities. The data cover: facility administration, resident movement, and resident characteristics (level of retardation, type of related conditions, age distribution, activities of daily living, moods, medical conditions, use of special equipment, and employment status). A basic description of the characteristics of nursing home residents with mental retardation and related conditions is also provided. Includes 29 references. (JDD)

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Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR): Program Utilization and Resident Characteristics

Project Report #31
March 1990

Center for Residential and Community Services
Institute on Community Integration
University of Minnesota

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Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR): Program Utilization and Resident Characteristics

Report #31

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EXECUTIVE SUMMARY

Since its enactment in 1971, the Intermediate Care Facility for the Mentally Retarded (ICF-MR) program under Title XIX of the Social Security Act has become the primary source of federal support of services to persons with mental retardation and related conditions. On June 30, 1988 more than 146,000 persons were residents of the 4,562 ICFs-MR located in all states except Arizona and Wyoming. Altogether during Fiscal Year 1988, expenditures for the residential and habilitation services received by these individuals exceeded 6 billion dollars, of which nearly 3.4 billion dollars were federal government reimbursements.

In 1981, amendment of Title XIX provided states with the option of requesting a waiver of certain Medical Assistance regulations to permit the provision of Home and Community-Based Services as an alternative for persons who would otherwise require ICF-MR services. This "Medicaid waiver" program has grown rapidly, with 80% of all states providing Home and Community Based Services on June 30, 1988 to a total of nearly 29,000 persons with mental retardation and related conditions at a Fiscal Year 1988 cost of about 450 million dollars.

In 1987 the Omnibus Budget Reconciliation Act (OBRA-87) required states to undertake screening and where appropriate improved habilitation activities or alternative placements for more than 40,000 persons with mental retardation living in nursing homes. These new requirements present substantial challenges to states as they seek to continue their nearly universal efforts to move greater numbers of people from institutions to community settings, to avoid new institution placements, and to deal with the growing numbers of people awaiting residential services.

In a May 1989 report (Lakin, Jaskulski, Hill, Bruininks, Menke, White, & Wright, 1989) states' perceptions and evolving policies related to the ICF-MR, Medicaid waiver and OBRA-87 requirements were described. The purpose of this report is primarily to provide a statistical update on the utilization of Medicaid ICF-MR, waiver and nursing home services for persons with mental retardation and related conditions and the characteristics of the service recipients. Data collection and analyses were carried out as part of the National Recurring Data Set Program on Residential Services funded by the Administration on Developmental Disabilities. Among the findings of this study were the following:

- *Growth of the ICF-MR program has slowed dramatically in the past several years.*
  - The June 30, 1988 total of 146,134 persons with mental retardation and related conditions in ICFs-MR was only 5,500 more than the total in 1982.
  - Growth after 1982 was much slower than in the 5 previous years. Between 1977 and 1982 the number of ICF-MR residents grew by 33,000, or from 106,166 to 140,682.
  - Between June 30, 1982 and 1988 a majority of states (27) actually decreased the total number of people living in ICFs-MR.

- *Populations of large ICFs-MR have decreased in the past several years.*
  - On June 30, 1988 there were 117,147 persons in ICFs-MR of 16 or more residents. This represented a 10% decrease from 130,968 on June 30, 1982.
  - On June 30, 1988 large ICF-MR residents included 85,064 people in state-operated facilities and 32,083 people in nonstate facilities.
  - On June 30, 1982 large ICF-MR residents included 107,356 people in state-operated facilities and 23,612 in nonstate facilities.

- On June 30, 1977 there were 104,456 residents of large ICFs-MR including 92,498 in state facilities and 11,958 in nonstate facilities.

- *There has been a continued growth in smaller community facilities in the ICF-MR program.*
  - On June 30, 1988 there were 28,987 residents of ICFs-MR with 15 or fewer residents. This represented a 200% increase over the previous 6 years. Small ICF-MR residents included 25,353 people in nonstate facilities and 3,634 people in state-operated facilities.
  - On June 30, 1982 there were 9,714 residents of small ICFs-MR including 8,362 residents of nonstate facilities and 1,352 residents of state-operated facilities.
  - On June 30, 1977 there were 1,710 residents in small ICFs-MR, including 1,354 in nonstate facilities and 356 in state-operated facilities.

- *A decreasing majority of ICF-MR residents reside in state-operated facilities.*
  - On June 30, 1988, 60.7% of residents of ICFs-MR were in state-operated facilities. This compares with 77.3% in 1982 and 87.5% in 1977.
  - The deconcentration of ICF-MR residents in state-operated facilities is associated with the general depopulation of state institutions and the increase in community ICFs-MR, 89% of which were operated by nonstate agencies.
  - Between June 30, 1977 and 1982 large state ICF-MR populations grew by 16% despite an overall 21% decrease in state institution populations (from 154,600 to 122,600) as states continued to certify previously uncertified units. By 1982 almost nine of ten state institution residents were in ICF-MR units and as state institution populations decreased by 22% between 1982 and 1988, residents of large state ICFs-MR decreased by 21%.

- *Since 1977 states have steadily consolidated the ICF-MR certification of large nonstate facilities.*
  - On June 30, 1977, 23% of the 52,718 persons in all large nonstate mental retardation facilities were in ICFs-MR.
  - On June 30, 1982, 41% of the 57,396 persons in all large nonstate mental retardation facilities were in ICFs-MR.
  - On June 30, 1988, 70% of the 45,907 persons in all large nonstate mental retardation facilities were in ICFs-MR.

- *States have increased certification of small ICFs-MR, but have remained generally reluctant to certify large proportions of their small facilities for ICF-MR participation.*
  - On June 30, 1988, only 20% of 125,507 persons living in small nonstate facilities were in ICFs-MR. This was a proportional increase of over 14% of 61,145 total small nonstate facility residents in 1982. However, the doubling of the total small nonstate facility residents nationwide between 1982 and 1988 was a greater factor in the increase from 8,362 to 25,353 small nonstate ICF-MR residents than were increases in the proportions of small nonstate facilities certified.
  - Small state operated facilities were relatively few (only about 4% of all small facility residents in 1988), but are much more likely to be ICF-MR certified (64.3% of small state facility residents are in ICFs-MR).

- *Small state ICFs-MR were highly concentrated in a few states.*
  - Of 417 small state ICFs-MR, 390 were in only 4 states.
  - Of 3,634 residents in all small state ICFs-MR, 64% lived in New York.
  - Only 12 states had any small state ICFs-MR.

- *Small nonstate ICFs-MR were concentrated in a few states.*
  - On June 30, 1988, 74.5% of all residents of small nonstate ICFs-MR were in 9 states.
  - On June 30, 1988, the 25 states with the lowest utilization together had only 2.3% of all small nonstate ICF-MR residents.
  - On June 30, 1988, one state alone accounted for 18% of all small nonstate ICF-MR residents.

- *There has been continued growth in waiver services.*
  - On June 30, 1982 there were only 1,605 waiver services recipients.
  - On June 30, 1986 there were 23,053 waiver service recipients.
  - On June 30, 1988 there were 28,689 waiver service recipients.

- *Growth in the total number of ICF-MR and waiver recipients has slowed substantially.*
  - Total increase from 1977 to 1982 was 36,121, averaging 7,224 per year.
  - Total increase from 1982 to 1986 was 24,955, averaging 6,239 per year.
  - Total increase from 1986 to 1988 was 7,581, averaging 3,791 per year.

- *Average size of large state ICFs-MR continues to decline.*
  - In 1977, large state ICFs-MR had an average 406 residents.
  - In 1982, large state ICFs-MR had an average 368 residents.
  - In 1988, large state ICFs-MR had an average 304 residents.

- *The average size of large nonstate ICFs-MR has decreased.*
  - In 1977, large nonstate ICFs-MR had an average 76 residents.
  - In 1982, large nonstate ICFs-MR had an average 66 residents.
  - In 1986, large nonstate ICFs-MR had an average 62 residents.
  - In 1988, large nonstate ICFs-MR had an average 61 residents.

- *Average size of small nonstate ICFs-MR decreased, then stabilized.*
  - Small nonstate ICFs-MR had an average 9.2 residents in 1977.
  - Small nonstate ICFs-MR had an average 8.0 residents in 1982.
  - Small nonstate ICFs-MR had an average 7.6 residents in both 1986 and 1988.

- *Average size of small state ICFs-MR was the same in 1988 as in 1977.*
  - In 1977, small state ICFs-MR had an average 8.7 residents.
  - In 1982, small state ICFs-MR had an average 8.6 residents.
  - In 1988, small state ICFs-MR had an average 8.7 residents.

- *Reduction in populations of large state ICFs-MR has been widespread.*
  - Between 1982 and 1988, 42 states reduced populations of large state ICFs-MR.
  - Between 1982 and 1988, only 7 states increased populations of large state ICFs-MR.

- *Recently, small ICFs-MR have been the most rapidly growing service model.*
  - Between 1986 and 1988, residents of large ICFs-MR declined in number by 6,152.
  - Between 1986 and 1988, recipients of waiver services increased by 5,636.
  - Between 1986 and 1988, residents of small ICFs-MR increased by 8,097.

- *From 1977 to 1988, residents of ICFs-MR serving six or fewer persons grew as a proportion of residents of all small ICFs-MR (i.e., those with 15 or fewer residents).*
  - In 1977, 16.7% of all residents of small ICFs-MR lived in ICFs-MR serving six or fewer persons.
  - In 1982, 26.5% of all residents of small ICFs-MR lived in ICFs-MR serving six or fewer persons.
  - In 1988, 31.3% of all residents of small ICFs-MR lived in ICFs-MR serving six or fewer persons.

- *From 1977 to 1988, residents of state ICFs-MR serving six or fewer persons declined as a proportion of all state and nonstate ICFs-MR serving six or fewer persons.*
  - In 1977, 12.5% of all residents of state and nonstate ICFs-MR serving six or fewer persons lived in state ICFs-MR.
  - In 1982, 8.1% of all residents of state and nonstate ICFs-MR serving six or fewer persons lived in state ICFs-MR.
  - In 1988, 4.7% of all residents of state and nonstate ICFs-MR serving six or fewer persons lived in state ICFs-MR.

- *ICF-MR facilities have a higher proportion of their resident populations made up of persons with mental retardation than noncertified facilities.*
  - Of all residents of mental retardation facilities, 96.2% were persons with mental retardation and related conditions.
  - Of all residents of noncertified facilities, 83.6% were persons with mental retardation and related conditions.
  - Of all residents of ICF-MR facilities, 96.3% were persons with mental retardation and related conditions.

- *Noncertified, private for profit facilities had the highest proportion of residents without mental retardation and related conditions.*
  - 23.7% of all residents of all private for profit facilities did not have mental retardation or related conditions.
  - 1.3% of all residents of for profit ICFs-MR did not have mental retardation or related conditions.
  - 32.3% of all residents of non-certified, private for profit facilities did not have mental retardation or related conditions.

- *Larger facilities were more likely to have their capacity Medicaid certified.*
  - Facilities with 800 or more residents were 100% Medicaid certified; those with 300-799 residents were 96.6% Medicaid certified; those with 76-299 residents were 66.9% Medicaid certified; and facilities of 16-75 residents were 31.3% Medicaid certified.
  - Only 22.1% of residents in facilities with 15 or fewer residents were in ICF-MR certified facilities.

- *Staff to resident ratios were highest in ICFs-MR.*
  - Staff to resident ratio in all mental retardation facilities was 1.06.1.
  - Staff to resident ratio in ICFs-MR was 1.33:1, as compared with 0.66:1 in noncertified facilities.

- *Staff to resident ratios were lower in small nonstate ICFs-MR.*
  - Staff to resident ratio in small ICFs-MR was .92:1.
  - Staff to resident ratio in small state ICFs-MR was 1.07:1.
  - Staff to resident ratio in small nonstate ICFs-MR was .90:1.

- *Staff to resident ratios were lowest in small non-ICF-MR for profit facilities.*
  - Staff to resident ratio in all small non-ICFs-MR was .66:1.
  - Staff to resident ratio in small for profit ICFs-MR was .60:1.
  - Staff to resident ratio in small for profit non-ICFs-MR was .44:1.

- *Large ICF-MR facilities had the highest proportion of persons with profound mental retardation.*
  - 54.5% of large ICF-MR populations were persons with profound mental retardation.
  - 17.4% of large non-ICF-MR populations were persons with profound mental retardation.
  - 13.6% of all small facilities' populations were persons with profound mental retardation.
  - 16.5% of small ICF-MR populations were persons with profound mental retardation.

- *Persons with related conditions, but not mental retardation were most likely to reside in non-ICFs-MR.*
  - Persons with related conditions were estimated to be less than 1% of the mental retardation facility population.
  - Persons with related conditions were 1.4% of the non-ICF-MR population.
  - Persons with related conditions were 0.6% of the ICF-MR population.

- *Death rates in both ICF-MR and noncertified facilities approximated the estimated national death rate in residential facilities.*
  - The estimated national death rate in all residential facilities was 1.4%.
  - The estimated death rate in ICFs-MR was 1.4%.
  - The estimated death rate in non-ICFs-MR was 1.5%.

- *Secondary conditions were more likely to be reported for persons with mental retardation as the severity of mental retardation increased.*
  - 29.6% of persons with mental retardation and related conditions in all facilities were reported to have epilepsy, including 15% of persons with mild mental retardation and 43% of persons with profound mental retardation.
  - 11.7% of persons with mental retardation and related conditions in all facilities were reported to have cerebral palsy, including 5.5% of persons with mild or borderline mental retardation and 19.5% of persons with profound mental retardation.
  - 7% of persons in all facilities were blind and/or deaf, including 2.3% of persons with mild or borderline mental retardation and 13.8% of persons with profound mental retardation.

- *The number and proportion of children and youth (0-21 years) in mental retardation facilities continued to decline.*
  - An adjusted estimate shows 17.9% of all facilities' population in 1987 to be children and youth, a decrease from 24.8% in 1982.
  - An estimated 13.7% of ICF-MR residents were under 21 in 1987, as compared with 22.6% in 1982.
  - Children and youth in state institutions declined from 25.8% of the population in June 1982 to 10.6% in June 1989.

- The above proportions of children and youth in all mental retardation facilities and in specialized institutional settings were far below the proportion of the national population in the birth to 21 year old range (32.5%).

- *Lower proportions of residents under 21 and higher proportions of residents over 55 were mildly or moderately retarded.*
  - In the 1987 National Medical Expenditure Survey an estimated 15.4% of all residents with mental retardation and related conditions were under 21 and 13.2% were over 55.
  - Residents under 21 made up 12.2% of all residents with mild or moderate mental retardation and 17.9% of all residents with severe or profound mental retardation.
  - Residents over 55 made up 16.1% of all residents with mild or moderate mental retardation and 10.6% of all residents with severe or profound mental retardation.

- *Although ability to perform activities of daily living (ADLs) varied widely by level of mental retardation, the majority of all residents could perform ADLs other than bathing and dressing.*
  - 39.1% of residents could bathe or shower independently.
  - 45.6% of residents could dress independently.
  - 67% of residents could use the toilet independently.
  - 80.3% of residents could get into and out of bed independently.
  - 77.2% of residents could feed themselves independently.
  - 77.3% of residents could walk across a room independently.

- *Residents of ICFs-MR were generally less able to perform instrumental activities of daily living than residents of non-ICFs-MR.*
  - 15.6% of ICF-MR residents and 41.6% of non-ICF-MR residents used the phone independently.
  - 8.7% of ICF-MR residents and 26.4% of non-ICF-MR residents shopped for personal items independently.
  - 9.3% of ICF-MR residents and 29.6% of non-ICF-MR residents used their own or public transportation independently.

- *ICF-MR residents were much less likely to be employed for pay away from their residence.*
  - 38.8% of persons with mental retardation were employed for pay, 26.3% away from their residence.
  - 32.1% of ICF-MR and 49.1% of non-ICF-MR residents were employed for pay.
  - 50.8% of residents of ICFs-MR with paid jobs and 85.1% of residents of non-ICFs-MR with paid jobs worked away from their residence.

- *Small ICF-MR residents were more likely to work with non-handicapped people.*
  - 15.8% of small ICF-MR residents worked with non-handicapped people.
  - 4.6% of large ICF-MR residents worked with non-handicapped people.
  - 8.4% of non-ICF-MR residents worked with non-handicapped people.

- *States continue to house tens of thousands of persons with mental retardation and related conditions in nursing homes.*
  - The 1987 National Medical Expenditure Survey (NMES) provided estimates of 45,261 persons with a primary diagnosis of mental retardation in nursing homes. States reported 42,700 persons with mental retardation in nursing homes on June 30, 1988.

- NMES estimated about 12,600 persons with other developmental disabilities in nursing homes in 1987.
- 1987 nursing home populations included an estimated 7,700 persons with a primary diagnosis of mental illness, but with mental retardation indicated and 24,800 persons with primary diagnosis of medical conditions but with mental retardation or related conditions indicated.

- *Persons with mental retardation and related conditions tend to be younger than the general nursing home population, but much older than the population of mental retardation facilities in general and ICFs-MR specifically.*
  - An estimated 88% of all nursing home residents in 1987 were 65 years or older as compared with 34% of those with a primary diagnosis of mental retardation or a related condition.
  - The estimated 34.4% of older (65+ years) nursing home residents with mental retardation or a related condition was much greater than the estimated 5.5% of all mental retardation facility residents and 5.8% of ICF-MR residents.

- *Despite total population increases of only 3.9% between 1982 and 1988, ICF-MR costs increased by about 60% over the same period.*
  - In 1982 total public expenditures for ICF-MR services to a total of 140,682 people (on June 30) were about 3.6 billion dollars.
  - In 1988 total public expenditures for ICF-MR services to a total of 146,134 people (on June 30) were about 6.03 billion dollars.
  - In 1977 the average daily per resident cost of ICF-MR care was $41.00. In 1982 it was $79.00. In 1988 it was $113.00.

- *Within the ICF-MR and waiver programs, by far the highest average per person federal reimbursements in 1988 were received by state-operated ICFs-MR.*
  - Average annual per resident federal reimbursements for large state ICFs-MR in 1988 were $28,000.
  - Average annual per resident federal reimbursement for large nonstate ICFs-MR were $14,000 per person.
  - Average annual federal reimbursements for residents of small state ICFs-MR were $27,500.
  - Average annual federal reimbursements for residents of small nonstate ICFs-MR were $17,500.
  - Average annual per recipient federal reimbursements for Medicaid waiver services were $8,800.

- *Daily cost per resident in ICFs-MR was likely to be higher than in non-ICFs-MR.*
  - 70% of all non-ICF-MR residents lived in facilities that cost $55 or less per day.
  - 17% of all ICF-MR residents lived in facilities that cost $55 or less per day.

INTERMEDIATE CARE FACILITIES FOR PERSONS WITH MENTAL RETARDATION (ICF-MR): PROGRAM UTILIZATION AND RESIDENT CHARACTERISTICS

Overview of Report

Introduction

This report on the Intermediate Care Facility for the Mentally Retarded (ICF-MR) and related programs under Title XIX (Medicaid) of the Social Security Act is the fourth since 1985. The frequency of these reports has been dictated primarily by the intense scrutiny given the ICF-MR program in recent years. That scrutiny was clearly evident in recent interviews with state officials about the ICF-MR program generally, and more specifically, how useful they saw it in meeting the challenges they currently face and/or anticipate in the future (see Lakin, Hill, Bruininks, Menke, White, & Wright, 1989).

Among the recurring themes of these state officials were: 1) the difficulties of providing appropriate, personalized services when the predominant service model (ICF-MR) is based on uniform standards for "facilities," 2) the unavoidable financial influences on service decisions when federal cost sharing is more readily available for some services (e.g., large institutions) than for others (e.g., semi-independent living), 3) the escalating costs of meeting minimum ICF-MR standards, 4) the difficulty of stabilizing or reducing public institution expenditures despite continued deinstitutionalization, 5) the challenge of meeting the needs for "active treatment" and/or more appropriate residential placements for people with mental retardation and related conditions now living in nursing homes; and 6) major pressures for service system expansion to respond to growing waiting lists, accompanied by a growing perception that this cannot be accomplished without greater efficiency, flexibility and equitable federal financial participation for all appropriate services. In large measure these same themes have been the focus of deliberations at the federal level regarding reform of Medicaid programs for persons with mental retardation and related conditions.

To the concerns noted by state officials may be added those found at the federal level about the growing costs of the ICF-MR program, from just over 1 billion dollars in FY 1977 to 6 billion dollars in FY 1988. There is also considerable debate about the extent to which the federal government should dictate, or at least influence substantially through different levels of financial participation, the size and nature of the service settings supported by federal funds. Such influence is often seen as contrary to the growing consensus that the best program decisions for individuals are made by those individuals and/or people who are particularly knowledgeable about their unique characteristics, abilities, needs and life circumstances. Such issues have dominated consideration of the need for significant reform of Medicaid's programs for persons with mental retardation throughout the 1980s. Presumably they will continue in the 1990s until some resolution is attained regarding the current incongruity between the generally perceived ideal service system for people with mental retardation and related conditions and the reality of the current Medicaid dominated system.

Purpose of Report

This report is not intended to directly respond to these concerns or possible means for their resolution. The concerns are real and are expressed by states throughout the nation (see Lakin et al., 1989). Reasonable legislative approaches to their resolution have been suggested. The purpose

of this report is simply to provide a description and an update of the status of the ICF-MR and related programs to assist in consideration of improvements to Medicaid services for persons with mental retardation and related conditions. The report contains three basic sections: 1) a brief background description of the key Medicaid programs of interest; 2) state-by-state and national statistics on ICF-MR and related Medicaid Home and Community Based Services and nursing home utilization; and 3) a description of the characteristics of ICF-MR facilities and their residents, with comparative statistics for noncertified facilities, as well as a basic description of the characteristics of nursing home residents with mental retardation and related conditions, as obtained in the Institutional Population Component of the 1987 National Medical Expenditure Survey.

PART I: BACKGROUND OF ICF-MR AND RELATED MEDICAID PROGRAMS*

Federal Involvement Prior to ICFs-MR

Federal involvement in care for individuals with mental retardation and related conditions is fairly recent in this country. In the nineteenth century, public funding of services for persons with mental retardation was limited to state and local governments' responsibility for almshouses and other public institutions. Private charity and voluntary associations, on the other hand, were the only source of support for people with mental retardation who were living outside those public institutions. In 1935, after five years of declining revenues during the Great Depression, the U.S. Congress enacted Titles I, IV, and X of the Social Security Act to provide federal funds with which states could begin to provide direct cash assistance for certain classes of dependent individuals, notably elderly, blind, orphans, and other "children deprived of parental support." The majority of recipients under these Titles were elderly persons living in their own homes. In fact, these initial Titles of the Social Security Act carefully precluded federal assistance for persons in institutional care, which was at the time becoming a growing burden to states. For example, from 1923 to 1935 the average daily populations of state mental retardation institutions nearly doubled from 48,000 to 90,000 (Lakin, 1979). Even persons who were elderly, blind, orphans, or other children deprived of parental support were not eligible for federal program participation if they resided in a public institution or in any institution for mental disease. When the Social Security Act was extended to include persons with disabilities under the Aid to the Permanently and Totally Disabled (Titles XIV and XVI) in 1950, the same prohibition extended to persons with disabilities living in institutions.

Major developments leading to federal participation in long-term care of persons with mental retardation came in the 1960s. Among these were the attention drawn to the needs of persons with mental retardation by the President's Panel on Mental Retardation, first appointed in 1961; the Maternal and Child Health and Mental Retardation Planning Amendments and the Mental Retardation Facilities and Community Mental Health Centers Construction Act, enacted in 1963; and, beginning with Senator Robert Kennedy's well-publicized inspections of New York State institutions in 1964, the national attention drawn to the inadequacy, abuse, and overcrowding within state institutions. Another important step in the eventual federal involvement in long-term care for persons with mental retardation came indirectly with the Kerr-Mills Act in 1960, which established open-ended federal reimbursement according to a federal-state matching formula to the states for medical assistance costs, even though the Act was originally limited to aged populations.

In 1965, Medicaid was enacted as Medical Assistance, Title XIX of the Social Security Act. It contained the structural characteristics of the Kerr-Mills Act, but extended medical assistance to people in the categories of blind, disabled, and dependent children and their families as well as to elderly people. Although at least some persons with mental retardation were thus included for Medical Assistance, Title XIX also carried forward the exclusions of otherwise eligible persons in public institutions (except "medical institutions") and in any institution for mental diseases. An exception was that states could claim Federal Financial Participation (FFP) for residents 65 years and older in psychiatric institutions which met established standards. Importantly, although persons in public mental retardation institutions were still excluded from coverage, otherwise eligible adult

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*The discussion on pages 3-5 was adapted from E. Boggs, K.C. Lakin, & S. Clauser (1985).

residents of private nursing homes, including facilities serving people with mental retardation, became qualified for Medicaid participation if the homes met established standards.

Thus Title XIX brought a number of incentives that were not necessarily beneficial to persons with mental retardation in long-term care settings. First, states were stimulated to concentrate the funds they had available for improving public institutions on their mental hospitals, virtually all of which had substantial numbers of residents 65 years or older. Indeed, on June 30, 1964 public mental institutions held 144,000 residents age 65 years or older, or, in comparison, about three-quarters as many people as were in state mental retardation institutions (Lakin, 1979; National Institute on Mental Health, 1975). In return for efforts to bring their mental hospitals into compliance with Title XIX standards, states were rewarded with federal contributions of at least half the costs of caring for residents who were elderly. Second, states had an incentive to convert their public institutions into "medical institutions," that is, Skilled Nursing Facilities (SNFs). Once done the residents were then eligible for inpatient coverage under Title XIX. Eleven states actually did so between 1966 and 1969. But as a General Accounting Office (1970) audit in 1970 noted, SNF standards generally required more medical services than most residents needed or, for that matter, actually received, and did so virtually to the exclusion of developmental programming. Finally, because FFP was available for residents with mental retardation in private facilities meeting either SNF or "intermediate care" (ICF) nursing home standards (the latter being under Title XI from 1967 until conjoined with Title XIX in 1971), it was relatively easy and financially beneficial for states to transfer people with mental retardation to private nursing homes. The effects of this policy are still felt today as nursing homes remain a major residential alternative, with an estimated 40,000 to 45,000 residents with a primary diagnosis of mental retardation in nursing homes nationwide (Lakin, Hill, & Anderson, in press; see also Parts II and III of this report). By 1970 the effects of these policies were increasingly viewed as detrimental to providing the kinds of residential care then considered most appropriate.

Establishment of the ICF-MR Program

It was only shortly after the introduction of federal reimbursement for skilled nursing care that the U.S. Senate noted rapid growth in the numbers of people who were becoming patients in Skilled Nursing Facilities. It was further documented that many of these individuals were receiving far more medical care than they actually needed, at a greater cost than was needed, largely because of the incentives of placing people in facilities for which half or more of the costs were reimbursed through the federal Title XIX program (U.S. Senate, 1967). Therefore, in 1967, a less medically oriented and less expensive "Intermediate Care Facility" (ICF) program for elderly and disabled adults was authorized under Title XI of the Social Security Act. Although ICF standards still primarily addressed medical and personal care needs, they required less intensive medical services than did the SNF standards. In 1971 the SNF and ICF programs were combined under Title XIX. Within the legislation combining the two programs was a little noticed, scarcely debated amendment that for the first time authorized FFP for "intermediate care" provided specifically in facilities for people with mental retardation. The authorization of Intermediate Care Facilities for the Mentally Retarded (ICF-MR) was the culmination of considerable lobbying on the part of the National Association for Retarded Citizens and a number of directors of state mental health or related agencies.

Three primary outcomes of the ICF-MR legislation appear to have been intended by Congress. First, the ICF-MR program was clearly intended to provide substantial federal stimulation through the availability of FFP for upgrading the physical environment and the quality of care and habilitation being provided in public mental retardation institutions. Second, it is probably fair to say

that there was intent to neutralize the previously existing incentives for states to place persons with mental retardation in nonstate nursing homes or certify their state institutions as SNFs in order to gain FFP. A third and related intention was to provide FFP for care and habilitation specifically designed to meet the specialized needs of persons with mental retardation--specifically, "active treatment" and "health or rehabilitative services" rather than focusing exclusively upon medical care. A fourth desired outcome, not as readily apparent as the first three and more doubtfully achieved, was that federal funding would only support, not supplant, the existing levels of state funding for residential services to result in improved conditions. (The requirement of state maintenance of effort actually expired in 1975.) Clearly, too, an outcome desired by many proponents of the new ICF-MR program, some of whom were in Congress, was to find a way for the federal government to assist states in affording the rapidly increasing costs of state institution care. States were experiencing average real dollar increases of 14% per year in the five years prior to the passage of the ICF-MR legislation, a real dollar growth rate even greater than that experienced since the ICF-MR legislation was enacted (Greenberg, Lakin, Hill, Bruininks, & Hauber, 1985).

The ICF-MR program was initiated in a period of rapid change in residential care for persons with mental retardation. For example, by Fiscal Year 1973 the population of state institutions had decreased to 173,775 from a high of 194,650 in Fiscal Year 1967 (Lakin, 1979). Public and professional perceptions about the appropriateness of large institutional care were clearly changing. Nevertheless, states overwhelmingly opted to participate in the ICF-MR program. Two notable outcomes were that 1) nearly every state took steps to secure federal participation in paying for state institution services, and 2) in order to maintain federal participation, most states were compelled to invest substantial amounts of state dollars in bringing institutions into conformity with ICF-MR standards. As evidence of these outcomes 40 states had at least one ICF-MR certified state institution by June 30, 1977. Nearly a billion state dollars were invested in institutional improvement efforts in Fiscal Years 1978-1980 alone, with a substantial majority of those dollars being invested in improvements directly related to meeting ICF-MR standards (Gettings & Mitchell, 1980).

In the context of growing support for community-based residential services, such statistics were used by a growing number of critics to charge that the ICF-MR program 1) had created direct incentives for maintaining people with mental retardation in state institutions by providing federal payment of from 50% to 80% of the costs of care in those facilities; 2) had diverted funds that could otherwise have been spent on more integrated, community-based programs into extremely costly institution renovations solely to obtain FFP; and 3) had promoted numerous inefficiencies (and often enhanced dependency) by promoting a single uniform standard for care and oversight of ICF-MR residents irrespective of the nature and degree of the residents' disabilities and/or their relative capacity for independence. These criticisms, and the growing desire to increase residential opportunities in community settings, along with the continued desire of states to avail themselves of the favorable federal cost-share for ICF-MR care, helped stimulate the development of small ICF-MR facilities and the eventual clarification by the Health Care Financing Administration (HCFA) of how the ICF-MR level of care could be delivered in relatively small (4-15 person) group homes.

Small ICF-MR Certified Facilities

The expansion of the ICF-MR program beyond use only for public institutions was a major development. Private residential facilities were not an issue at the time of original enactment, probably because: 1) most of the total capacity of private facilities was already technically covered under the 1967 amendments to the Social Security Act authorizing private ICF programs, and 2) in

1971 state facilities were by far the predominant model of residential care. Indeed, the 1969 Master Facility Inventory indicated a total population in nonstate mental retardation facilities of about 25,000, compared with a state mental retardation institution population of 190,000 (Lakin, Bruininks, Doth, Hill, & Hauber, 1982).

Significantly, although Congressional debate had focused on public institutions, the statute did not specifically limit ICF-MR coverage, standards, or reimbursement to publicly operated facilities. The definition of "institution" which serves as the basis for participation in the ICF-MR program is the one that also covers the general ICF institution. This definition includes facilities serving "four or more people in single or multiple units" (45 CFR Sec. 448.60 (6) (1)). Although it cannot be determined whether Congress, in authorizing a "four or more bed" institution, purposely intended the ICF-MR benefit to be available in small facilities, it does seem reasonable to suppose, in the absence of specific limitations, that Congress was more interested in improving the general quality of residential care than it was in targeting specific types of facilities. Regulations governing ICF-MR certification, published in January 1974, also supported the option of developing relatively small facilities. These regulations delineated two categories of ICFs-MR, those housing 16 or more and those housing 15 or fewer residents. Further, the regulations contained several specifications that allowed greater flexibility in meeting the standards for small facilities.

Despite the regulatory provisions which recognized and to some extent facilitated the development of small ICFs-MR, the numbers of such facilities actually developed varied enormously among states. Furthermore, while states in some DHHS regions (e.g., Region V) had developed hundreds of small ICF-MR certified facilities, other regions (e.g., II and X) had none. The variations among states and regions reflected what some states and national organizations considered a failure of HCFA to delineate clear and consistent policy guidelines for certifying small facilities for ICF-MR participation and/or reluctance on the part of some regional HCFA agencies to promote the option for states to do so. Such criticisms were seen as evidence of a lack of commitment within HCFA to support the expressed federal goal of deinstitutionalization.

In response to continued complaints from the states that there was a need to clarify policy regarding the certification of small ICFs-MR, in 1981 HCFA issued "Interpretive Guidelines" for certifying small facilities. These guidelines did not change the existing standards for the ICF-MR program. Their purpose was simply to clarify how the existing standards for ICF-MR certification could be applied to programs delivering the ICF-MR level of care in facilities with 4 to 15 residents. Even though the guidelines did not substantially affect the options available to states under the ICF-MR program, they were viewed as important in demonstrating the degree of flexibility available in providing the ICF-MR level of care. It is also clearly the case that publication of the guidelines was followed by substantially greater numbers of states exercising the option to develop small ICFs-MR. Ironically, these guidelines were published in the same year (1981) that Congress enacted legislation that would give even greater programmatic flexibility to states in their use of Medicaid funding, the Medicaid Home and Community-Based Services waiver authority (Section 2176 of P.L. 97-35).

Intensified Federal Look-Behind

The federal Health Care Financing Administration (HCFA) provides federal oversight of state implementation of the ICF-MR program. The oversight includes development of standards for providing the ICF-MR services authorized by Congress and monitoring of state efforts to assure that ICF-MR providers are in compliance with federal program standards. Congressional hearings in 1984

gave considerable attention to reports of poor quality and abusive conditions in some residential settings that states had certified as ICFs-MR for federal financial participation. Particular interest centered on two problems: 1) delegation to states of responsibility to monitor their own state institutions; and 2) limited effort by HCFA to ensure that state certification efforts were sufficient to assure compliance with ICF-MR standards. As a result of the 1984 hearings, Congress allocated funds for over 50 new positions at HCFA to carry out substantially intensified federal "look behinds" of state program review efforts. Not only did federal oversight efforts become more numerous but they also shifted markedly from review of administrative procedures and compliance with basic health and safety standards to direct monitoring of residential and habilitation services ("active treatment") provided to residents. The look behind surveys resulted in numerous corrective actions being required. Many corrections required higher ratios of staff to residents, especially among the professional staff whose availability is considered integral to the concept of active treatment as defined in federal regulations. Many states were required to increase staffing levels and/or reduce populations of large state facilities in order to maintain their ICF-MR certification. Some facilities, primarily older state institutions, also were cited for numerous deficiencies related to the physical plant. Although frequently described as a difficult experience, the look behind surveys have been seen by many as helpful in improving program quality, in stimulating improvements in the quality assurance process itself, and in helping to clarify the rationale for state agency preferences for community-based residential services (Lakin et al., 1989). However, required corrections were described as so costly in some cases as to reduce significantly the amount of funding available for expansion of community-based services. This was particularly true where substantial increase in staffing levels or major capital improvements were necessary. Perhaps most relevant to the ongoing debate about the future role of the ICF-MR program in the evolution of residential services, there has been considerable doubt expressed by government officials and advocates alike about whether the generally costly corrections required actually had a notably positive effect on the quality of life and active treatment received by residents, particularly those in large institutions (Lakin et al., 1989).

Phase Down Option

The ultimate sanction that may result from state or federal findings of non-compliance with federal regulations by an ICF-MR can be termination of the provider agreement, thereby making the ICF-MR ineligible for reimbursement of costs under Medicaid. In practice, few terminations of provider agreements have resulted from the intensified review of ICF-MR programs since 1985. Other actions have been taken to require corrections by ICFs-MR found not in compliance with federal standards. Nevertheless, threat of termination of a provider's agreement is a powerful incentive. There was concern that states might, under threat of terminations for non-compliance, expend funds to bring facilities into compliance that might be used more effectively to develop community services. As a result, the Consolidated Omnibus Reconciliation Act of 1985 (P.L. 99-272) contained provision for an optional response to deficiencies identified in federal look behind surveys. To correct deficiencies, an ICF-MR facility could employ a planned phase down of all or part of the facility that would extend beyond the normal time periods allowed for compliance, provided that the deficiencies did not pose a "significant threat" to residents' health or safety. Final regulations for this program were published in January 1988, with the provisions of the phase down option interpreted by HCFA as being applicable only to deficiencies identified in surveys conducted after the regulations were published. Since this interpretation did not allow states to use the option for facilities found deficient in surveys conducted between 1985 and 1987, the option has been of little use to date in avoiding large scale investment in inefficient and obsolete facilities and had virtually no effect on the June 30, 1988 utilization data presented in this report.

New ICF-MR Regulations

In June 1988, the Health Care Financing Administration (HCFA) published revised regulations to govern the ICF-MR program, effective in October 1988. These regulations included a number of significant changes in the conditions for participation in the ICF-MR program. While the changes are too numerous to outline in detail here, the increased flexibility in ways by which facilities can meet the various service requirements of the 1971 legislation is noteworthy. At the same time, considerably increased attention has been given in the new regulations to the conditions for "active treatment" and "client behavior and facility practices." In the new standards it is clear that ICFs-MR will be expected to pursue aggressive, planful and monitored programs of treatment. It is also clear that HCFA considers persons who are not in need of "active treatment" to be persons who, "by definition," are inappropriately placed in ICFs-MR. Whether this will have effects over time on the ICF-MR placement of persons with relatively mild levels of impairment which frequently is the case in small community-based, ICFs-MR is not clear. However, it is clear from data presented in Part III that there are on average few differences between people living in community-based ICFs-MR and those living in other community facilities.

Medicaid Waiver

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35), passed on August 13, 1981, established the Medicaid Home and Community-Based Services waiver authority. Under this section, the Secretary of Health and Human Services was granted the authority to waive certain existing Medicaid requirements and allow states to finance certain "non-institutional" services for Medicaid-eligible individuals. The waiver was designed to provide home and community-based services for people who are aged, blind, disabled, or mentally retarded or who have a related condition and who, in the absence of alternative services, would remain in or would be placed in a Medicaid facility (i.e., Skilled Nursing Facility, an Intermediate Care Facility, or an Intermediate Care Facility for the Mentally Retarded). These waivers were operated under interim rules from October 1981 until March 1985, when the final regulations were published.

Non-institutional services that can be provided under the waiver include case management, personal care services, adult day health services, habilitation services, respite care, or any other service that a state can show will lead to decreased costs for Medicaid funded long-term care. Although not allowed to use the waiver to pay for room and board, virtually all states that use the waiver for persons with mental retardation do provide a portion of residential service under the categories of personal care, habilitation, and homemaker services, while in most instances using cash assistance from other Social Security Act programs to fund the room and board portion of the residential care program. Given both its flexibility and its potential for promoting the goal of community-based care and habilitation, the waiver has generally been recognized as having considerable potential in assisting states in the provision of community-based services as an alternative to institutional care.

The overriding fiscal principle in providing waiver services is that a state must explain in its waiver application how, if it uses the waiver to provide non-institutional, community-based services, the total amount of state Medicaid expenditures will not exceed total expenditures in the absence of the waiver. States have used two main arguments in justifying these assurances: 1) that existing ICF-MR capacity can be "closed" (people would be deinstitutionalized and not replaced) as a result of services provided through the waiver; and/or 2) that new ICF-MR capacity that otherwise would have been opened will not be opened because people will be diverted from institutional care as a result

of the services provided through the waiver. Two recent publications (Lakin et al., 1989; Smith & Gettings, 1989) have documented both the attractiveness of the waiver option to states in providing noninstitutional services and the sense of frustration they feel in having their utilization of this option directly linked to reduced ICF-MR utilization. Most states today seek substantive Medicaid reform that would provide the kinds of flexibility to provide services outside ICF-MR certified settings as available under the waiver, but without the specific limits on beneficiaries or amount of federal funding now experienced under the Medicaid waiver (Lakin et al., 1989). Legislative proposals attempting to provide such flexibility through changes in the Medicaid program for persons with mental retardation and related conditions have been introduced in both Houses of the U.S. Congress.

Nursing Home Restrictions

Almost from the inception of Medicaid long-term care benefits concern was expressed about the reimbursement incentives created for states to place persons with mental retardation and related conditions in nursing facilities (National Association for Retarded Citizens, 1975). There was a sense among the advocacy community that many more people with mental retardation and related conditions were living in nursing homes than could be thought to be appropriately served in them. In time supportive documentation became available. For example a 1985 study of 2,700 nursing home residents with mental retardation and related conditions (Davis, Silverstein, Uehara, & Sadden, 1987) concluded that only 10% needed services warranting nursing home placement. In 1987 Congress responded to these and other criticisms of nursing home care in the Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203). Provisions of this legislation were intended to reduce and eliminate inappropriate placements of persons with mental disorders in nursing homes. They restricted criteria for admissions to Medicaid reimbursed nursing facilities, so that only those persons requiring the medical/nursing services offered could be admitted. Current residents not in need of nursing services were required to be moved to "more appropriate" residential facilities, with the exception of individuals living in a specific nursing home for more than 30 months should they choose to stay. In either case nursing facilities are required to assure that each person's needs for active treatment are met. Presumably this legislation will have a substantial effect on both the numbers and experiences of people with mental retardation and related conditions living in nursing homes.

New Proposals for Title XIX Reform

The predominance of large institutions within the ICF-MR program in a period when community-based care is generally believed to be, and is rather consistently demonstrated to be preferable to institutional care (Larson & Lakin, 1989), continues to focus critical attention on the ICF-MR program. Clarifications regarding small ICFs-MR, the creation of the Medicaid waiver option, and revised ICF-MR regulations published in 1988 have assisted states in using Medicaid long-term care funds for settings other than large institutions. But as will be seen in the statistics presented in this report, the combined number of all residents of small (4-15 resident), community ICFs-MR and waiver service recipients still includes only about a third of the total number of all ICF-MR and waiver service recipients. Because of this imbalance a great deal of attention has been given in recent years to the advisability of open-ended federal cost-sharing of a single model of long-term care while other, often more desirable and better integrated options (e.g., foster care, semi-independent living) have limited access to federal support. Critics of contemporary federal policy note further that it is the families who care for their own disabled members who are least likely to receive needed support from public programs, even though "family care" is recognized as often the most desirable and almost always least costly of the residential possibilities for persons with mental

retardation and related conditions (see, for example, Mitchell, 1987). Bills currently introduced in both the U.S. Senate and House of Representatives have attempted to respond to these concerns.

Beginning in 1983, Senator John Chafee of Rhode Island has introduced a series of three bills designed to respond to criticisms of the current ICF-MR program. The most recent version was first introduced in 1987 as the "Medicaid Home and Community Quality Services Act" and not being acted upon in the 100th Congress was reintroduced in 101st Congress in 1989. This proposed legislation would significantly amend Title XIX and its provisions for persons with mental retardation and related conditions. Among the bill's more visible features are that it would make open-ended Medicaid funding available for services to people in natural, adoptive, or foster family homes and in small individual or group living arrangements while essentially freezing the real dollar federal contributions to states for services to people in large facilities (16 or more residents). The bill would require states to provide several community and family support services (case management; individual and family supports such as attendant care, respite care, assistive and communicative devices; vocational services and protective intervention against abuse and neglect). Other community-based services could be optional for participating states. Each state would be required to develop a specific implementation strategy that would define the component parts of its program, including the standards and procedures for assuring the quality of services provided in the state's program.

In the House of Representatives, Henry Waxman and colleagues introduced the "Medicaid Community and Facility Habilitation Amendments of 1989." This bill was actually approved in the House of Representatives as one part of the massive omnibus budget reconciliation package of 1989. However, lacking the passage of companion legislation in the Senate, it was one of many programs deleted in the final Senate/House compromise bill. The new 1990 Medicaid Community and Facility Habilitation Amendments bill is essentially the same as the earlier bill. The major aspect of the bill that responds to current state concerns is the authorization for states to provide community habilitation and supportive services as an optional Medicaid program. However, states for the most part are unhappy with a number of proposals within the bill. These include federal determination of the standards for community services, job protection requirements for institutional workers displaced by phase-down of institutional services, the making of most current regulatory standards for ICFs-MR (relabeled "habilitative facilities") statutory with increased enforcement provisions, and establishment of very demanding requirements for state financial maintenance of effort. Senator Exon of Nebraska has also introduced this bill in the U.S. Senate.

The statistics presented in this paper focus on topics of utilization, change, and beneficiary characteristics in the ICF-MR program and in a more limited way certain related programs. Many of these findings are directly relevant to the ongoing evaluation of present Medicaid policy at the federal level. They show where the ICF-MR and Medicaid waiver programs currently stand in terms of utilization, where they have been, and with cautious extrapolation where they appear to be heading. In the discussion of findings Medicaid programs are often treated as though they are a single federal program. To the extent that they derive from a common federal entitlement program they are. But Medicaid programs are ultimately shaped by the policies of individual states and states vary dramatically in their Medicaid funded residential programs. Therefore, the data in Part II on program utilization are presented for individual states as well as the nation as a whole. These data also show longitudinal national trends in Title XIX services for persons with mental retardation and related conditions, when compared with data obtained from earlier studies by the Center for Residential and Community Services. Part III then uses data gathered on 3,618 persons with mental retardation and related conditions sampled as part of the National Medical Expenditure Survey of

1987 to describe certain characteristics of people in ICFs-MR and to compare them with data on people in noncertified facilities. An additional sample of 204 persons with mental retardation and related conditions were identified among the 3,347 total individuals sampled in nursing homes as part of the same National Medical Expenditure Survey. Hopefully those data together can contribute to evaluating current Medicaid programs, the challenges facing them, and the possibilities for their reform.

PART II: UTILIZATION OF ICFs-MR AND RELATED MEDICAID PROGRAMS

Method

Since 1976, the Center for Residential and Community Services (CRCS) has been conducting individual facility and state agency surveys that have permitted periodic evaluation of the number, size, and type of facilities participating in the ICF-MR program, the number and characteristics of persons residing in them, and the number of people with mental retardation and related conditions receiving Medicaid waiver services.

Facility Surveys, 1977 and 1982

In 1977-1978 CRCS, with funding from the Administration on Developmental Disabilities, undertook a survey as of June 30, 1977 of all state-licensed, state-contracted, or state-operated residential facilities in the United States serving persons who were mentally retarded/developmentally disabled. In 1982, CRCS received primary funding from the Health Care Financing Administration (HCFA), with supplemental support from the Administration on Developmental Disabilities, to replicate the earlier study as of June 30, 1982. In both studies, an identical operational definition of residential facility was employed:

> Any living quarter(s) which provided 24-hour, 7-days-a-week responsibility for room, board, and supervision of mentally retarded people as of June 30, 1977/1982, with the exception of: (a) single family homes providing services to a relative; (b) nursing homes, boarding homes, and foster homes that are not formally state licensed and contracted as mental retardation service providers; and (c) independent living programs that have no staff residing in the same facility.

Both studies gathered data on both ICF-MR certified and non-certified facilities. The specific methods for identifying and surveying these facilities is described in Lakin, Hill, and Bruininks (1985). There were a total of 574 ICF-MR certified facilities in operation in 1977 and 1,853 in operation on June 30, 1982.

State Agency Surveys, 1985 and 1988

Since 1985 statistics on ICF-MR and noncertified facility utilization and related statistics have been gathered as part of the "Recurring Data Set Program," funded by the Administration on Developmental Disabilities. This project actually began in 1978, but data collection until 1985 was limited to state-operated facilities. A 1984 feasibility study indicated that in all but three states, through state mental retardation and/or state Medicaid agencies, it was possible to obtain statistics on the total number of ICF-MR certified facilities and facility residents by state/nonstate facility operation and by size (15 or fewer/16 or more residents) as of June 30. In addition, all but 3 states indicated the ability to report the number of Medicaid waiver recipients and nursing home residents as of June 30, or the last day of the state fiscal year. As part of the feasibility study, key data sources were also identified in each state for the new data elements.

Beginning for Fiscal Year 1985 the Recurring Data Set Program was expanded to include state and nonstate ICF-MR and noncertified facilities, broken down into size categories of large (16 or more residents) and small (15 or fewer residents). For Fiscal Year 1986 recipients of Medicaid

waiver services and nursing home residents with mental retardation and related conditions were also added. In 1988 a third size category (6 or fewer residents) was added to the survey. Response rates for these various data elements have been 98% or greater for every year since 1985. Missing data for a specific year have been estimated by the latest available data from that state. In 1988, response rates were 98% for all data elements with Massachusetts only able to report 1987 statistics.

Findings

General Overview

Growth in use of the ICF-MR program, rapid during the first decade following its enactment, slowed dramatically after 1982. An increase of less than 5,500 ICF-MR residents over six years, from 140,682 on June 30, 1982 to 146,134 on June 30, 1988, contrasted sharply with the rise of over 33,000 in ICF-MR population during the preceding five years. While growth in the use of the ICF-MR program slowed markedly in its second decade, a new program alternative for persons eligible for ICF-MR care contributed to a continuing increase in the total number of ICF-MR eligible Title XIX beneficiaries. Following enactment in 1981, the Title XIX waiver Home and Community-Based Services (HCBS) program expanded rapidly. On June 30, 1988, 28,689 persons, 16.4% of the combined ICF-MR and Medicaid waiver beneficiaries were receiving Medicaid Home and Community Based ("waiver") Services.

In addition to a significantly reduced rate of growth in the total number of ICF-MR residents and a rapid increase in the number of waiver services recipients, the number of residents in large (i.e., 16 or more residents) ICFs-MR continued to decline, from 130,968 on June 30, 1982 to 117,280 on June 30, 1988. During the same period, use of small (i.e., 15 or fewer residents) ICFs-MR increased by more than 19,000 residents. Of this increase, about one-third occurred in ICFs-MR of six or less residents.

Overall, from 1982 to 1988, the nature of Medicaid participation in the service system for persons with mental retardation and related conditions changed substantially in the direction of community-based services. In 1982 the 9,714 small ICF-MR residents and 1,605 Medicaid waiver recipients made up 8% of the total ICF-MR and Medicaid waiver recipients. On June 30, 1988, 57,676 persons lived in small ICFs-MR or received Medicaid waiver services. Together, these community programs served some 33% of the total ICF-MR and waiver beneficiaries. In Fiscal Year 1982, the Federal expenditures for these community-based programs were 5.8% of the combined federal ICF-MR and waiver expenditures. By 1988 they were about 22% of the combined federal funding.

In the following pages statistics on the status and change in the ICF-MR program are also presented with respect to the state or nonstate operation of facilities. Historically ICF-MR services have been provided primarily in state-operated facilities. On June 30, 1977, 87.5% of 106,166 total ICF-MR service recipients lived in state-operated facilities. On June 30, 1982, 77.3% of 140,682 ICF-MR recipients lived in state-operated facilities. On June 30, 1988, 60.7% of 146,134 ICF-MR recipients lived in state-operated facilities. The steady decrease in the proportion of ICF-MR recipients living in state-operated facilities is a result of substantial depopulation of state institutions over the period and the development of a community-based residential care system primarily made up of private service providers.

Statistics in Part II of this report are presented on a state by state basis. This reflects the fact that Medicaid ICF-MR and Medicaid waiver programs are state option programs. States provide them if they choose, where they choose, and, save the restrictions noted above in waiver utilization, to as many people as they choose. The "national program" is merely the accumulation of programs which states develop based on their individual perceptions of the benefits of program participation. Because states' perceptions of benefit vary considerably, so too does the nature and size of their ICF-MR programs (see Lakin et al., 1989, for a discussion of these perceptions). Therefore, as will be discussed later, state participation in the ICF-MR program varies from including less than one-third of total residential populations in 7 states to including more than two-thirds in 10 states.

The discussion of the status and change in the ICF-MR program that follows is based on the statistics presented in Tables 1 through 6. Tables 1, 2, 3 and 4 present statistics on ICF-MR facilities and residents by state, size, and state/nonstate operation on June 30, 1977, June 30, 1982, June 30, 1986, and June 30, 1988, respectively. Table 5 shows the net change among the states in these same categories between 1982 and 1988. Table 6 compares June 30, 1988 ICF-MR utilization with the total residential care system in each of the states on the same date.

Nonstate ICF-MR Certified Facilities

The period from 1977 to 1988 produced a steady and significant shift toward nonstate operation of ICFs-MR. In 1977 the 13,312 nonstate ICF-MR residents made up only 12.5% of all ICF-MR residents. By 1982, 31,974 nonstate ICF-MR residents made up 22.7% of all ICF-MR residents. By 1986, 49,875 nonstate ICF-MR residents made up 34.6% of all ICF-MR residents. On June 30, 1988, 57,436 or 39.3% of all ICF-MR residents were in nonstate ICFs-MR. Growth in the number of nonstate ICF-MR residents has been evident in both large and small nonstate facilities.

Large nonstate facilities. Since 1977 there has been a strong trend toward greater "privatization" of all residential care, including that provided in ICFs-MR. While as part of this process the growth in the number of residents in small nonstate ICFs-MR between 1977 and 1986 was proportionally more rapid and generally more attended to than the growth in the number of residents in large nonstate ICFs-MR, there was actually a larger net population increase in large ICFs-MR than in small ones from 1977 to 1986 (19,987 and 16,576, respectively). However, from 1982 to 1988, increase of residents in small nonstate ICFs-MR was twice that in large nonstate facilities. Small facilities grew by 16,991 residents, as compared with 8,471 in large ICFs-MR.

Table 1: ICF-MR Certified Facilities and Residents on June 30, 1977

	Facilities									Residents								
	State			Nonstate			All By Size			State			Nonstate			All by Size		
	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total
Alabama	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Alaska	0	1	1	1	1	2	1	2	3	0	105	105	10	20	30	10	125	135
Arizona	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Arkansas	0	5	5	0	2	2	0	7	7	0	1,338	1,338	0	47	47	0	1,385	1,385
California	0	4	4	0	0	0	0	4	4	0	0	0	0	0	0	0	0	0
Colorado	1	3	4	7	5	12	8	8	16	8	4,158	4,166	65	306	371	73	4,464	4,537
Connecticut	8	7	15	2	0	2	10	7	17	85	583	668	19	0	19	104	583	687
Delaware	0	1	1	0	0	0	0	1	1	0	477	477	0	0	0	0	477	477
D.C.	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Florida	0	4	4	1	2	3	1	6	7	0	279	279	15	76	91	15	355	370
Georgia	0	6	6	0	0	0	0	6	6	0	2,369	2,369	0	0	0	0	2,369	2,369
Hawaii	0	1	1	0	0	0	0	1	1	0	524	524	0	0	0	0	524	524
Idaho	0	1	1	0	1	1	0	2	2	0	553	553	0	30	30	0	583	583
Illinois	0	13	13	0	26	26	0	39	39	0	2,568	2,568	0	2,785	2,785	0	5,353	5,353
Indiana	0	2	2	0	0	0	0	2	2	0	1,026	1,026	0	0	0	0	1,026	1,026
Iowa	0	2	2	0	0	0	0	2	2	0	1,432	1,432	0	0	0	0	1,432	1,432
Kansas	0	4	4	0	6	6	0	10	10	0	1,443	1,443	0	367	367	0	1,810	1,810
Kentucky	0	3	3	0	4	4	0	7	7	0	469	469	0	530	530	0	999	999
Louisiana	0	10	10	0	4	4	0	14	14	0	3,221	3,221	0	461	461	0	3,682	3,682
Maine	0	2	2	0	4	4	0	6	6	0	197	197	0	113	113	0	310	310
Maryland	0	6	6	0	0	0	0	6	6	0	1,367	1,367	0	0	0	0	1,367	1,367
Massachusetts	0	7	7	0	0	0	0	7	7	0	4,242	4,242	0	0	0	0	4,242	4,242
Michigan	0	12	12	0	0	0	0	12	12	0	5,760	5,760	0	0	0	0	5,760	5,760
Minnesota	0	8	8	113	33	146	113	41	154	0	2,527	2,527	1,052	1,724	2,776	1,052	4,251	5,303
Mississippi	0	2	2	0	2	2	0	4	4	0	255	255	0	236	236	0	491	491
Missouri	0	5	5	0	4	4	0	9	9	0	1,842	1,842	0	209	209	0	2,051	2,051
Montana	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Nebraska	0	3	3	0	3	3	0	6	6	0	958	958	0	398	398	0	1,356	1,356
Nevada	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
New Hampshire	0	1	1	0	1	1	0	2	2	0	264	264	0	24	24	0	288	288
New Jersey	0	5	5	0	0	0	0	5	5	0	525	525	0	0	0	0	525	525
New Mexico	0	2	2	0	0	0	0	2	2	0	426	426	0	0	0	0	426	426
New York	0	24	24	3	1	4	3	25	28	0	18,401	18,401	36	164	200	36	18,565	18,601
North Carolina	0	6	6	0	1	1	0	7	7	0	2,003	2,003	0	70	70	0	2,073	2,073
North Dakota	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Ohio	0	11	11	6	12	18	6	23	29	0	1,696	1,696	44	748	792	44	2,444	2,488
Oklahoma	0	3	3	0	0	0	0	3	3	0	1,978	1,978	0	0	0	0	1,978	1,978
Oregon	0	2	2	0	4	4	0	6	6	0	1,781	1,781	0	208	208	0	1,989	1,989
Pennsylvania	0	19	19	0	3	3	0	22	22	0	6,935	6,935	0	420	420	0	7,355	7,355
Rhode Island	0	1	1	1	0	1	1	1	2	0	756	756	7	0	7	7	756	763
South Carolina	5	7	12	0	2	2	5	9	14	40	903	943	0	74	74	40	977	1,017
South Dakota	0	2	2	0	0	0	0	2	2	0	540	540	0	0	0	0	540	540
Tennessee	0	4	4	0	2	2	0	6	6	0	2,111	2,111	0	38	38	0	2,149	2,149
Texas	27	16	43	7	8	15	34	24	58	223	9,497	9,720	54	712	766	277	10,209	10,486
Utah	0	1	1	0	7	7	0	8	8	0	849	849	0	344	344	0	1,193	1,193
Vermont	0	1	1	0	0	0	0	1	1	0	352	352	0	0	0	0	352	352
Virginia	0	5	5	0	1	1	0	6	6	0	3,508	3,508	0	50	50	0	3,558	3,558
Washington	0	3	3	0	8	8	0	11	11	0	0	0	0	440	440	0	440	440
West Virginia	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Wisconsin	0	3	3	6	11	17	6	14	20	0	2,280	2,280	52	1,364	1,416	52	3,644	3,696
Wyoming	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U.S. Total	41	228	269	147	158	305	188	386	574	356	92,498	92,854	1,354	11,958	13,312	1,710	104,456	106,166
% ICF-MR Totals	7.1	39.7	46.9	25.6	27.5	53.1	32.8	67.2	100.0	.3	87.1	87.5	1.3	11.3	12.5	1.6	98.4	100.0

Most of the growth in the number of residents in large nonstate certified facilities over the past decade took place between 1977 and 1982 (an increase of 11,654), as states actively pursued certifying existing nonstate institutions. But the certification of large nonstate facilities continued at a high rate until 1986, after which net increase in number of large nonstate ICFs-MR virtually ceased. From June 30, 1977 to June 30, 1982 states were on the average increasing large nonstate ICF-MR institution populations by 2,330 per year; from June 30, 1982 to June 30, 1986 the average annual increase was 2,080, or only 250 fewer. From June 30, 1986 to June 30, 1988 this increase virtually stopped, averaging less than 70 residents per year. It is also worthwhile to note that although the average size of large nonstate facilities decreased from 76 to 66 residents between 1977 and 1982, between 1982 and 1986 their average size decreased only from 66 to 62 residents, and from 1986 to 1988 to 61 residents. The net national increase of 8,333 residents in large nonstate ICF-MR between 1982 and 1986 was substantial, but not truly a national trend. It was caused by a few states actively undertaking certification of previously existing large nonstate facilities. In fact, three states alone accounted for 57% of the 1982-1986 increase of residents in large, nonstate ICF-MR institutions: Ohio (1,826), Florida (1,240), and Oklahoma (1,647). In the case of Oklahoma this increase not only did not represent newly established facilities, it did not even represent new Medicaid funding. The Oklahoma increase came from the recertification of mental retardation facilities that were previously certified ICF-general. The relative stability in large nonstate facilities from 1986 to 1988 was virtually nationwide, with the largest increase (409 residents) reported by Oklahoma and the largest decrease (356 residents) reported by California.

Small nonstate facilities. Small nonstate ICFs-MR have been afforded a great deal of attention in recent years. The primary reason for this attention is, of course, that with the exception of residential services funded under the Medicaid waiver, small ICFs-MR have been the only way for states to use the favorable federal-state cost-share under Medicaid to support community-based residential programs. On June 30, 1988 small nonstate ICFs-MR made up about two-thirds (73.2%) of all of certified facilities. On the other hand, only 17.3% of residents of ICFs-MR lived in small nonstate facilities. These numbers compare with 26% of facilities and 1.3% of residents in 1977, 56% of facilities and 6% of residents in 1982, and 68.5% of facilities and 12.4% of residents in 1986.

The development of small nonstate ICFs-MR has varied considerably from state-to-state since passage of the ICF-MR legislation. The extreme of the tendency was most evident in 1977 when Minnesota, the earliest adopter of the small ICF-MR option, had within its residential care system 77% of all small nonstate ICF-MR group homes nationwide (113) and 78% of all small nonstate ICF-MR residents. By 1982, small nonstate ICFs-MR were no longer predominantly a Minnesota program, but there remained a strong tendency toward concentration in a few states. On June 30, 1982, Minnesota and New York together had a majority (51.5%) of all residents nationally (28.8% and 22.7%, respectively). The five states which were the most intense users of small nonstate ICF-MR programs in 1982 (Minnesota, New York, Michigan, Indiana, and Rhode Island) together had 67.6% of all residents, as compared with only 21.5% of residents of all ICF-MR certified facilities. By 1988, the five most intense users of small nonstate ICF-MR programs in 1982 (Minnesota, New York, Michigan, Indiana, and Rhode Island) had less than half of all small nonstate ICF-MR residents (49.6%) and half the facilities (50.0%), while their share of all ICF-MR residents increased slightly to 22.6%. On June 30, 1977 only 10 states had 1 or more small nonstate ICF-MR. That number had increased to 35 in 1982, and to 39 in 1986, and to 40 in 1988. On June 30, 1988 nine states (California, Illinois, Indiana, Louisiana, Michigan, Minnesota, New York, Ohio, and Texas) together accounted for about three-fourths (74.5%) of all small nonstate ICF-MR residents, while

Table 2: ICF-MR Certified Facilities and Populations On June 30, 1982

	Facilities									Residents								
	State			Nonstate			All By Size			State			Nonstate			All by Size		
	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total
Alabama	0	4	4	0	0	0	0	4	4	0	1,470	1,470	0	0	0	0	1,470	1,470
Alaska	0	1	1	3	0	3	3	1	4	0	88	88	30	0	30	30	88	118
Arizona	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Arkansas	0	5	5	0	2	2	0	7	7	0	1,354	1,354	0	66	66	0	1,420	1,420
California	0	8	8	0	29	29	0	37	37	0	7,924	7,924	0	2,450	2,450	0	10,374	10,374
Colorado	0	3	3	25	9	34	25	12	37	0	1,264	1,264	207	546	753	207	1,810	2,017
Connecticut	21	11	32	9	1	10	30	12	42	233	1,264	1,497	80	21	101	313	1,285	1,598
Delaware	0	1	1	0	0	0	0	1	1	0	513	513	0	0	0	0	513	513
D.C.	0	1	1	1	2	3	1	3	4	0	372	372	4	60	64	4	432	436
Florida	0	7	7	6	12	18	6	19	25	0	1,407	1,407	63	658	721	63	2,065	2,128
Georgia	0	8	8	0	1	1	0	9	9	0	2,381	2,381	0	110	110	0	2,491	2,491
Hawaii	1	1	2	0	0	0	1	1	2	8	379	387	0	0	0	8	379	387
Idaho	0	1	1	7	3	10	7	4	11	0	350	350	55	77	132	55	427	482
Illinois	0	15	15	5	38	43	5	53	58	0	4,500	4,500	64	3,580	3,644	64	8,080	8,144
Indiana	0	7	7	57	3	60	57	10	67	0	2,296	2296	337	165	502	337	2,461	2,798
Iowa	0	3	3	0	8	8	0	11	11	0	1,296	1,296	0	377	377	0	1,673	1,673
Kansas	0	4	4	4	11	15	4	15	19	0	1,371	1,371	54	653	707	54	2,024	2,078
Kentucky	0	3	3	0	6	6	0	9	9	0	677	677	0	573	573	0	1,250	1,250
Louisiana	2	10	12	30	12	42	32	22	54	3	3,496	3,499	245	1,105	1,350	248	4,601	4,849
Maine	1	2	3	18	5	23	19	7	26	12	364	376	122	132	254	134	496	630
Maryland	1	9	10	0	0	0	1	9	10	10	1,841	1,851	0	0	0	10	1,841	1,851
Massachusetts	0	8	8	9	0	9	9	8	17	0	3,897	3,897	70	74	74	3,897	3,971	
Michigan	22	11	33	117	0	117	139	11	150	133	3,165	3,298	704	0	704	837	3,165	4,002
Minnesota	0	8	8	260	42	302	260	50	310	0	2,417	2,417	2,412	2,070	4,482	2,412	4,487	6,899
Mississippi	0	5	5	0	6	6	0	11	11	0	999	999	0	615	615	0	1,614	1,614
Missouri	0	5	5	8	0	8	8	5	13	0	1,813	1,813	65	0	65	65	1,813	1,878
Montana	0	2	2	2	0	2	2	2	4	0	273	273	17	0	17	17	273	290
Nebraska	1	2	3	4	3	7	5	5	10	13	558	571	29	380	409	42	938	980
Nevada	0	2	2	1	1	2	1	3	4	0	160	160	15	0	15	15	160	175
New Hampshire	0	1	1	0	1	1	0	2	2	0	317	317	0	22	22	0	339	339
New Jersey	0	9	9	0	0	0	0	9	9	0	4,366	4,366	0	0	0	0	4,366	4,366
New Mexico	0	2	2	6	0	6	6	2	8	0	503	503	50	0	50	50	503	553
New York	44	23	67	254	10	264	298	33	331	390	12,502	12,892	1,899	786	2,685	2,289	13,288	15,577
North Carolina	1	7	8	2	2	4	3	9	12	5	2,582	2,587	15	160	175	20	2,742	2,762
North Dakota	0	1	1	2	1	3	2	2	4	0	183	183	24	12	36	24	195	219
Ohio	8	23	31	9	45	54	17	68	85	67	3,908	3,975	90	1,975	2,065	157	5,883	6,040
Oklahoma	0	3	3	0	0	0	0	3	3	0	1,803	1,803	0	0	0	0	1,803	1,803
Oregon	2	2	4	3	5	8	5	7	12	19	1,627	1,646	37	235	272	56	1,862	1,918
Pennsylvania	0	20	20	41	15	56	41	35	76	0	7,128	7,128	274	1,196	1,470	274	8,324	8,598
Rhode Island	9	1	10	51	1	52	60	2	62	74	482	556	307	18	325	381	500	881
South Carolina	12	10	22	3	3	6	15	13	28	109	2,409	2,518	24	123	147	133	2,532	2,665
South Dakota	0	2	2	11	0	11	11	2	13	0	601	601	120	0	120	120	601	721
Tennessee	0	4	4	9	5	14	9	9	18	0	2,125	2,125	72	180	252	72	2,305	2,377
Texas	31	17	48	55	44	99	86	61	147	258	10,118	10,376	610	2,973	3,583	868	13,091	13,959
Utah	0	1	1	0	7	7	0	8	8	0	793	793	0	406	406	0	1,199	1,199
Vermont	0	2	2	12	0	12	12	2	14	0	314	314	71	0	71	71	314	385
Virginia	2	6	8	3	1	4	5	7	12	18	3,506	3,524	32	60	92	50	3,566	3,616
Washington	0	6	6	7	11	18	7	17	24	0	1,894	1,894	57	513	570	57	2,407	2,464
West Virginia	0	1	1	1	1	2	1	2	3	0	156	156	4	16	20	4	172	176
Wisconsin	0	4	4	9	13	22	9	17	26	0	2,150	2,150	99	1,299	1,398	99	3,449	3,548
Wyoming	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U.S. Total	158	292	450	1,044	359	1,403	1,202	651	1,853	1,352	107,356	108,708	8,362	23,612	31,974	9,714	130,968	140,682
% ICF-MR Totals	8.5	15.8	24.3	56.3	19.4	75.7	64.9	35.1	100.0	1.0	76.3	77.3	5.9	16.8	22.7	6.9	93.1	100.0

New York alone accounted for 18%. In contrast, the 25 states with the lowest utilization of small nonstate ICFs-MR had only 2.3% of all residents on June 30, 1988.

The proportion of small nonstate ICF-MR residents living in facilities of 6 or fewer residents grew from 18.4% in 1977, to 28.3% in 1982 to 34.1% in 1988. Over the same period the average size of small nonstate ICFs-MR decreased from 9.2 residents in 1977, to 8.0 in 1982 to 7.6 in 1988.

State ICF-MR Certified Facilities

Although the proportion of ICF-MR residents living in nonstate facilities has been increasing steadily, ICF-MR services are still delivered primarily in state-operated facilities (60.7% of all ICF-MR residents). Similarly, federal ICF-MR reimbursements, although increasingly shifting toward nonstate facilities, still primarily go to state-operated facilities (73.6% of all federal reimbursements). Even though there was substantial growth in small state-operated ICFs-MR between 1986 and 1988 (23% increase) state-operated ICF-MR services remained largely institutional, with only 4.1% of the June 30, 1988 populations in facilities of 15 or fewer residents.

Large state facilities. Nationally in Fiscal Year 1988, the average daily population of state mental retardation institutions was about 91,582, or at about the same number as in 1936 (Lakin, 1979; White, Lakin, & Bruininks, 1989). Although the percentage of state institution residents living in ICF-MR certified units increased from 88% to 92.8% between 1982 and 1988, there was an overall reduction in the population of large state ICF-MR institutions. From June 30, 1982 to June 30, 1988 there was a net decrease of about 22,292 residents of ICF-MR certified state institutions in the U.S. This trend toward lower numbers of residents in ICF-MR certified state institutions was evident in the vast majority of states. Only 7 states increased the number of residents in their state ICF-MR institutions and of these only 3 increased by more than 13 residents (Mississippi, 74; North Dakota, 131; and West Virginia, 56).

In contrast, between June 30, 1977 and June 30, 1982, 26 states increased the number of residents in ICF-MR certified state institutions by 13 or more residents, with a net increase of about 15,000. Two major factors affected the rather notable change from an average increase of about 3,000 per year between 1977 and 1982 to an average decrease of about 3,700 per year between 1982 and 1988. First, between June 30, 1977 and June 30, 1982 states were increasing the proportion of state institution "beds" with ICF-MR certification from about 60% of the national total to about 88%. Therefore, although states were decreasing their state institution populations over the period by about a quarter, the number of newly certified facilities led to an overall increase in persons living in ICF-MR certified state institutions. However, by 1982, with the vast majority of institution beds already ICF-MR certified, the ongoing depopulation of state institutions caused substantial decreases in the number of residents in ICF-MR certified state institutions. Despite the decreasing populations in state institutions, which continues to reduce the extent to which the ICF-MR program remains predominantly an institution-centered program, clearly it remains such. In June 1988, 58.2% of all ICF-MR residents were in large state institutions; but this compares with 63.4% in 1986, 76.3% in 1982 and 87.1% in 1977.

Table 3: ICF-MR Certified Facilities and Residents on June 30, 1986

	Facilities									Residents								
	State			Nonstate			All By Size			State			Nonstate			All by Size		
	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total
Alabama	0	5	5	3	0	3	3	5	8	0	1,333	1,333	31	0	31	31	1,333	1,364
Alaska	0	1	1	5	0	5	5	1	6	0	59	59	40	0	40	40	59	99
Arizona	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Arkansas	0	6	6	0	3	3	0	9	9	0	1,284	1,284	0	88	88	0	1,372	1,372
California	0	8	8	213	34	247	213	42	255	0	5,043	5,043	1,455	2,918	4,373	1,455	7,961	9,416
Colorado	0	3	3	0	6	6	0	9	9	0	969	969	0	346	346	0	1,315	1,315
Connecticut	27	10	37	15	1	16	42	11	53	537	509	1,046	88	15	103	625	524	1,149
Delaware	0	1	1	8	0	8	8	1	9	0	394	394	61	0	61	61	394	455
D.C.	0	1	1	51	0	51	51	1	52	0	285	285	306	0	306	306	285	591
Florida	0	4	4	3	48	51	3	52	55	0	1,303	1,303	42	1,898	1,940	42	3,201	3,243
Georgia	0	8	8	0	1	1	0	9	9	0	1,872	1,872	0	110	110	0	1,982	1,982
Hawaii	1	1	2	4	0	4	5	1	6	8	221	229	20	0	20	28	221	249
Idaho	0	1	1	12	3	15	12	4	16	0	287	287	100	82	182	100	369	469
Illinois	0	12	12	26	46	72	26	58	84	0	4,475	4,475	338	4,140	4,478	338	8,615	8,953
Indiana	0	9	9	229	5	234	229	14	243	0	2,302	2,302	1,450	608	2,058	1,450	2,910	4,360
Iowa	0	2	2	5	13	18	5	15	20	0	1,143	1,143	37	836	873	37	1,979	2,016
Kansas	0	4	4	13	10	23	13	14	27	0	1,345	1,345	166	626	792	166	1,971	2,137
Kentucky	0	3	3	0	6	6	0	9	9	0	690	690	0	513	513	0	1,203	1,203
Louisiana	6	9	15	144	15	159	150	24	174	34	3,042	3,076	874	1,625	2,499	908	4,667	5,575
Maine	2	2	4	34	4	38	36	6	42	26	295	321	314	89	403	340	384	724
Maryland	1	7	8	0	0	0	1	7	8	13	2,203	2,216	0	0	0	13	2,203	2,216
Massachusetts	0	7	7	38	0	38	38	7	45	0	3,438	3,438	299	0	299	299	3,438	3,737
Michigan	0	8	8	229	0	229	229	8	237	0	1,930	1,930	1,384	0	1,384	1,384	1,930	3,314
Minnesota	0	7	7	294	53	347	294	60	354	0	1,780	1,780	2,753	2,319	5,072	2,753	4,099	6,852
Mississippi	0	5	5	0	5	5	0	10	10	0	967	967	0	605	605	0	1,572	1,572
Missouri	2	9	11	12	3	15	14	12	26	14	1,858	1,872	90	126	216	104	1,984	2,088
Montana	0	2	2	1	0	1	1	2	3	0	257	257	9	0	9	9	257	266
Nebraska	0	1	1	0	4	4	0	5	5	0	468	468	0	393	393	0	861	861
Nevada	0	2	2	1	0	1	1	2	3	0	166	166	15	0	15	15	166	181
New Hampshire	0	2	2	7	1	8	7	3	10	0	226	226	50	23	73	50	249	299
New Jersey	0	9	9	0	2	2	0	11	11	0	3,809	3,809	0	72	72	0	3,881	3,881
New Mexico	0	2	2	16	0	16	16	2	18	0	514	514	135	0	135	135	514	649
New York	181	28	209	442	35	477	623	63	686	1,664	10,705	12,369	3,647	1,083	4,730	5,311	11,788	17,099
North Carolina	0	6	6	33	4	37	33	10	43	0	2,492	2,492	210	402	612	210	2,894	3,104
North Dakota	0	2	2	58	0	58	58	2	60	0	437	437	441	0	441	441	437	878
Ohio	0	21	21	121	84	205	121	105	226	0	3,073	3,073	912	3,801	4,713	912	6,874	7,786
Oklahoma	0	3	3	0	17	17	0	20	20	0	1,354	1,354	0	1,647	1,647	0	3,001	3,001
Oregon	0	2	2	2	6	8	2	8	10	0	1,294	1,294	22	261	283	22	1,406	1,577
Pennsylvania	0	17	17	80	20	100	80	37	117	0	5,647	5,647	517	1,573	2,090	517	7,220	7,737
Rhode Island	10	2	12	84	0	84	94	2	96	61	335	396	511	0	511	572	335	907
South Carolina	11	6	17	27	3	30	38	9	47	101	2,660	2,761	229	110	339	330	2,770	3,100
South Dakota	0	2	2	16	0	16	16	2	18	0	497	497	166	0	166	166	497	663
Tennessee	0	4	4	12	4	16	12	8	20	0	2,128	2,128	95	188	283	95	2,316	2,411
Texas	57	16	73	93	31	124	150	47	197	502	8,327	8,829	803	2,417	3,220	1,305	10,744	12,049
Utah	0	1	1	1	9	10	1	10	11	0	700	700	15	604	619	15	1,304	1,319
Vermont	0	1	1	11	0	11	11	1	12	0	195	195	66	0	66	66	195	261
Virginia	0	5	5	9	3	12	9	8	17	0	2,970	2,970	91	108	199	91	3,078	3,169
Washington	0	6	6	21	12	33	21	18	39	0	1,839	1,839	138	618	756	138	2,457	2,595
West Virginia	0	2	2	1	2	3	1	4	5	0	204	204	10	51	61	10	255	265
Wisconsin	0	3	3	0	22	22	0	25	25	0	2,030	2,030	0	1,650	1,650	0	3,680	3,680
Wyoming	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U.S. Total	298	278	576	2,374	515	2,889	2,672	793	3,465	2,960	91,354	94,314	17,930	31,945	49,875	20,890	123,299	144,189
% ICF-MR Totals	8.6	8.0	16.6	68.5	14.9	83.4	77.1	22.9	100.0	2.1	63.4	65.4	12.4	22.2	34.6	14.5	85.5	100.0

Table 4: ICF-MR Certified Facilities and Residents on June 30, 1988

	Facilities									Residents								
	State			Nonstate			All By Size			State			Nonstate			All by Size		
	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total
Alabama	0	5	5	3	0	3	3	5	8	0	1,333	1,333	31	0	31	31	1,333	1,364
Alaska	0	1	1	5	0	5	5	1	6	0	57	57	50	0	50	50	57	107
Arizona	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Arkansas	1	6	7	0	4	4	1	10	11	12	1,302	1,314	0	139	139	12	1,441	1,453
California	0	7	7	274e	33	307	274e	40	314	0	6,826	6,826	1,483	2,562	4,045	1,483	9,388	10,871
Colorado	36	3	39	0	6	6	36	9	45	274	529	803	0	346e	346e	274	875	1,149
Connecticut	36	11	47	33	1	34	69	12	81	277	938	1,215	181	18	199	458	956	1,414
Delaware	0	1	1	10	0	10	10	1	11	0	374	374	65	0	65	65	374	439
D.C.	0	1	1	61	0	61	61	1	62	0	256	256	410	0	410	410	256	666
Florida	0	4	4	0	51	51	0	55	55	0	1,250	1,250	0	1,930	1,930	0	3,180	3,180
Georgia	0	8	8	0	1	1	0	9	9	0	1,803	1,803	0	110	110	0	1,913	1,913
Hawaii	0	2	2	21e	0	21e	21e	2	23e	0	210	210	86e	0	86e	86e	210e	296
Idaho	0	1	1	28	2	30	28	3	31	0	236	236	170e	55e	225e	170e	291e	461
Illinois	0	12	12	118	46	164	118	58	176	0	4,513	4,513	1,792	4,041	5,833	1,792	8,554	10,346
Indiana	0	8	8	351	6	357	351	14	365	0	1,725	1,725	2,402	563	2,965	2,402	2,288	4,690
Iowa	0	2	2	6	19	25	6	21	27	0	1,056	1,056	59	725	784	59	1,781	1,840
Kansas	0	4	4	15	10	25	15	14	29	0	1,237	1,237	183	661	844	183	1,898	2,081
Kentucky	0	3	3	0	6	6	0	9	9	0	674	674	0	513e	513e	0	1,187e	1,187
Louisiana	5	9	14	253	16	269	258	25	283	30	2,789	2,819	1,545	1,652	3,197	1,575	4,441	6,016
Maine	2	2	4	30	6	36	32	8	40	24	290	314	219	144	363	243	434	677
Maryland	1	7	8	0	0	0	1	7	8	11	1,418	1,429	0	0	0	11	1,418	1,429
Massachusetts	3e	7e	10e	39e	0e	39e	42e	7e	49e	24e	3,367e	3,391e	307e	0e	307e	331e	3,367e	3,698
Michigan	0	8	8	370	0	370	370	8	378	0	1,436	1,436	2,247	0	2,247	2,247	1,436	3,683
Minnesota	0	7	7	284	49	333	284	56	340	0	1,471	1,471	2,675	2,193	4,868	2,675	3,664	6,339
Mississippi	0	5	5	0	5	5	0	10	10	0	1,073	1,073	0	605	605	0	1,678	
Missouri	2	10	12	19	3	22	21	13	34	15	1,570	1,585	145	138	283	160	1,708	1,868
Montana	0	2	2	1	0	1	1	2	3	0	243	243	10	0	10	10	243	253
Nebraska	0	1	1	1	2	3	1	3	4	0	472	472	8	328	336	8	800	808
Nevada	0	2	2	1	0	1	1	2	3	0	173	173	15	0	15	15	173	188
New Hampshire	0	2	2	8	0	8	8	2	10	0	144	144	60	0	60	60	144	204
New Jersey	0	9	9	0	2	2	0	11	11	0	3,745	3,745	0	70e	70e	0	3,815	3,815
New Mexico	0	2	2	24	0	24	24	2	26	0	507	507	202	0	202	202	507	709
New York	243	37	280	532	38	570	775	75	850	2,314	9,507	11,821	4,493	1,253	5,746	6,807	10,760	17,567
North Carolina	0	6	6	74	4	78	74	10	84	0	2,569	2,569	474	402	876	474	2,971	3,445
North Dakota	0	1	1	61	1	62	61	2	63	0	314	314	550	24	574	550	338	888
Ohio	0	16	16	125	89	214	125	105	230	0	2,479	2,479	1,127	3,929	5,056	1,127	6,408	7,535
Oklahoma	0	3	3	0	23	23	0	26	26	0	1,186	1,186	0	2,056	2,056	0	3,242	3,242
Oregon	0	2	2	2	3	5	2	5	7	0	1,098	1,098	22	164	186	22	1,262	1,284
Pennsylvania	0	14	14	122	23	145	122	37	159	0	4,606	4,606	815	1,943	2,758	815	6,549	7,364
Rhode Island	12	2	14	131	0	131	143	2	145	68	261	329	764	0	764	832	261	1,093
South Carolina	1	5	6	94	3	97	95	8	103	14	2,422	2,436	788	76	864	802	2,498	3,300
South Dakota	0	2	2	17	0	17	17	2	19	0	434	434	216	0	216	216	434	650
Tennessee	0	4	4	1	4	5	1	8	9	0	1,986e	1,986	12	200	212	12	2,186	2,198
Texas	75	17	92	149	31	180	224	48	272	571	7,933	8,504	1,121	2,586	3,707	1,692	10,519	12,211
Utah	0	1	1	3	10	13	3	11	14	0	485	485	45	415	460	45	900	945
Vermont	0	1	1	9	0	9	9	1	10	0	184	184	54	0	54	54	184	238
Virginia	0	5	5	14	3	17	14	8	22	0	2,774	2,774	136	108	244	136	2,882	3,018
Washington	0	6	6	24	11	35	24	17	41	0	1,801	1,801	166	572	738	166	2,373	2,539
West Virginia	0	2	2	20	2	22	20	4	24	0	212	212	154	51	205	154	263	417
Wisconsin	0	3	3	5	15	20	5	18	23	0	1,796	1,796	71	1,511	1,582	71	3,307	3,378
Wyoming	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U.S. Total	417	279	696	3,338	528	3,866	3,755	807	4,562	3,634	85,064	88,698	25,353	32,083	57,436	28,987	117,147	146,134
% ICF-MR Totals	9.14	6.12	15.26	73.17	11.57	84.74	82.31	17.69	100.00	2.49	58.21	60.70	17.35	21.95	39.30	19.84	80.16	100.00

Table 5: Net Change in ICF-MR Facilities and Residents by Facility Size and Type from June 30, 1982 to June 30, 1988

	Facilities									Residents								
	State			Nonstate			All by Size			State			Nonstate			All by Size		
	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total	1-15	16+	Total
Alabama	0	1	1	3	0	3	3	1	4	0	-137	-137	31	0	31	31	-137	-106
Alaska	0	0	0	2	0	2	2	0	2	0	-31	-31	20	0	20	20	-31	-11
Arizona	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Arkansas	1	1	2	0	2	2	1	3	4	12	-52	-40	0	73	73	12	21	33
California	0	-1	-1	274	4	278	274	3	277	0	-1,098	-1,098	1,483	112	1,595	1,483	-986	497
Colorado	36	0	36	-25	-3	-28	11	-3	8	274	-735	-461	-207	-200	-407	67	-935	-868
Connecticut	15	0	15	24	0	24	39	0	39	44	-326	-282	101	-3	98	145	-329	-184
Delaware	0	0	0	10	0	10	10	0	10	0	-139	-139	65	0	65	65	-139	-74
D.C.	0	0	0	60	-2	58	60	-2	58	0	-116	-116	406	-60	346	406	-176	230
Florida	0	-3	-3	-6	39	33	-6	36	30	0	-157	-157	-63	1,272	1,209	-63	1,115	1,052
Georgia	0	0	0	0	0	0	0	0	0	0	-578	-578	0	0	0	0	-578	-578
Hawaii	-1	1	0	21	0	21	20	1	21	-8	-169	-177	86	0	86	78	-169	-91
Idaho	0	0	0	21	-1	20	21	-1	20	0	-114	-114	115	-22	93	115	-136	-21
Illinois	0	-3	-3	113	8	121	113	5	118	0	13	13	1,728	461	2,189	1,728	474	2,202
Indiana	0	1	1	294	3	297	294	4	298	0	-571	-571	2,065	398	2,463	2,065	-173	1,892
Iowa	0	-1	-1	6	11	17	6	10	16	0	-240	-240	59	348	407	59	108	167
Kansas	0	0	0	11	-1	10	11	-1	10	0	-134	-134	129	8	137	129	-126	3
Kentucky	0	0	0	0	0	0	0	0	0	0	-3	-3	0	-60	-60	0	-63	-63
Louisiana	3	-1	2	223	4	227	226	3	229	27	-707	-680	1,300	547	1,847	1,327	-160	1,167
Maine	1	0	1	12	1	13	13	1	14	12	-74	-62	97	12	109	109	-62	47
Maryland	0	-2	-2	0	0	0	0	-2	-2	1	-423	-422	0	0	0	1	-423	-422
Massachusetts	3	-1	2	30	0	30	33	-1	32	24	-530	-506	233	0	233	257	-530	-273
Michigan	-22	-3	-25	253	0	253	231	-3	228	-133	-1,729	-1,862	1,543	0	1,543	1,410	-1,729	-319
Minnesota	0	-1	-1	24	7	31	24	6	30	0	-946	-946	263	123	386	263	-823	-560
Mississippi	0	0	0	0	-1	-1	0	-1	-1	0	74	74	0	-10	-10	0	64	64
Missouri	2	5	7	11	3	14	13	8	21	15	-243	-228	80	138	218	95	-105	-10
Montana	0	0	0	-1	0	-1	-1	0	-1	0	-30	-30	-7	0	-7	-7	-30	-37
Nebraska	-1	-1	-2	-3	-1	-4	-4	-2	-6	-13	-86	-99	-21	-52	-73	-34	-138	-172
Nevada	0	0	0	0	-1	-1	0	-1	-1	0	13	13	0	0	0	0	13	13
New Hampshire	0	1	1	8	-1	7	8	0	8	0	-173	-173	60	-22	38	60	-195	-135
New Jersey	0	0	0	0	2	2	0	2	2	0	-621	-621	0	70	70	0	-551	-551
New Mexico	0	0	0	18	0	18	18	0	18	0	4	4	152	0	152	152	4	156
New York	199	14	213	278	28	306	477	42	519	1,924	-2,995	-1,071	2,594	467	3,061	4,518	-2,528	1,990
North Carolina	-1	-1	-2	72	2	74	71	1	72	-5	-13	-18	459	242	701	454	229	683
North Dakota	0	0	0	59	0	59	59	0	59	0	131	131	526	12	538	526	143	669
Ohio	-8	-7	-15	116	44	160	108	37	145	-67	-1,429	-1,496	1,037	1,954	2,991	970	525	1,495
Oklahoma	0	0	0	0	23	23	0	23	23	0	-617	-617	0	2,056	2,056	0	1,439	1,439
Oregon	-2	0	-2	-1	-2	-3	-3	-2	-5	-19	-529	-548	-15	-71	-86	-34	-600	-634
Pennsylvania	0	-6	-6	81	8	89	81	2	83	0	-2,522	-2,522	541	747	1,288	541	-1,775	-1,234
Rhode Island	3	1	4	80	-1	79	83	0	83	-6	-221	-227	457	-18	439	451	-239	212
South Carolina	-11	-5	-16	91	0	91	80	-5	75	-95	13	-82	764	-47	717	669	-34	635
South Dakota	0	0	0	6	0	6	6	0	6	0	-167	-167	96	0	96	96	-167	-71
Tennessee	0	0	0	-8	-1	-9	-8	-1	-9	0	-139	-139	-60	20	-40	-60	-119	-179
Texas	44	0	44	94	-13	81	138	-13	125	313	-2,185	-1,872	511	-387	124	824	-2,572	-1,748
Utah	0	0	0	3	3	6	3	3	6	0	-308	-308	45	9	54	45	-299	-254
Vermont	0	-1	-1	-3	0	-3	-3	-1	-4	0	-130	-130	-17	0	-17	-17	-130	-147
Virginia	-2	-1	-3	11	2	13	9	1	10	-18	-732	-750	104	48	152	86	-684	-598
Washington	0	0	0	17	0	17	17	0	17	0	-93	-93	109	59	168	109	-34	75
West Virginia	0	1	1	19	1	20	19	2	21	0	56	56	150	35	185	150	91	241
Wisconsin	0	-1	-1	-4	2	-2	-4	1	-3	0	-354	-354	-28	212	184	-28	-142	-170
Wyoming	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
U.S. Total	259	-13	246	2,294	169	2,463	2,553	156	2,709	2,282	-22,292	-20,010	16,991	8,471	25,462	19,273	-13,821	5,452

Note. Some net change data are based on estimated numbers provided by states for June 30, 1988.

Small state facilities. On June 30, 1988 there was a total of 417 small state-operated, ICF-MR certified group homes operating in the United States. In all, only 2.5% (3,634) of all ICF-MR residents lived in these facilities. While the number of small ICFs-MR, and the number of residents in them, grew rapidly from 1982 to 1988, growth in the number of small state-operated facilities was largely confined to three states which had 90% of all new facilities and 95.9% of new residents. Of the total 417 small state ICFs-MR, 243 (58.3%) were in New York, 75 (18%) were in Texas, and both Colorado and Connecticut had 36 (8.6%), for a combined total of 93.5% of all small state-operated ICFs-MR.

Figure 1 shows the distribution of residents among the four types of facilities described above. The substantial growth in the number of residents in ICFs-MR other than state institutions is clear, but so, too, is the extent to which large state institutions remain the predominant setting for delivering ICF-MR residential services.

Large and Small Certified Facilities

Since the early years of the ICF-MR program the single most pronounced trend has been its evolution from an almost exclusively state facility program to a program increasingly delivered by nonstate providers. In recent years, however, state/nonstate operation has been less often seen as the most significant variable for categorizing residential facilities. Today policy considerations regarding the ICF-MR program much more often focus on facility size rather than operation. Increasingly facility size is seen as the most significant policy manipulable factor associated with qualities considered important in residential settings, notably normalized, integrated living, development of increased independence, and opportunities for social relationships and community participation. Although facilities with 15 residents are not particularly small by contemporary standards, they are frequently classified as small because of historical distinctions between 15 and smaller and 16 and more residents in fire safety codes and in the original ICF-MR standards. For some unspecified reason the revised 1988 ICF-MR regulations made distinctions in the standards between facilities of 16 and fewer residents and 17 and more residents, but we have retained the 15 and fewer/16 and more resident dichotomy for longitudinal comparative purposes. Even the proposed "Medicaid Home and Community Quality Services Act," while limiting newly developed "community living facilities" to no more than 3 times the size of the average household in an area (generally about 8 people), would allow existing residential facilities of 15 or fewer residents to still be considered "community living facilities" (i.e., small, noninstitutional settings) for the purposes of the bill.

With respect to the distinction between large and small ICFs-MR, Table 6 reports the total number of persons with mental retardation in large and small ICFs-MR, the number of persons with mental retardation in all large and small facilities licensed or operated by the various states for persons with mental retardation (irrespective of ICF-MR certification), and the percentages of all residents of large and small mental retardation facilities residing in ICF-MR certified settings on June 30, 1988.

Table 6 shows a total of 28,987 persons in small ICFs-MR nationwide on June 30, 1988. These persons made up only 19.8% of all ICF-MR residents on that day. These figures represent an increase of some 8,000 residents and 5% of total ICF-MR residents since 1986. However, states varied greatly in their particular use of large and small ICFs-MR. States with at least 40% of their total ICF-MR population in small facilities included Alaska (46.7%), Indiana (51.2%), District of

Figure 1

Residents of ICF-MR Certified Facilities
by Size and State/Nonstate Operation on
June 30 of 1977, 1982, 1986, and 1988

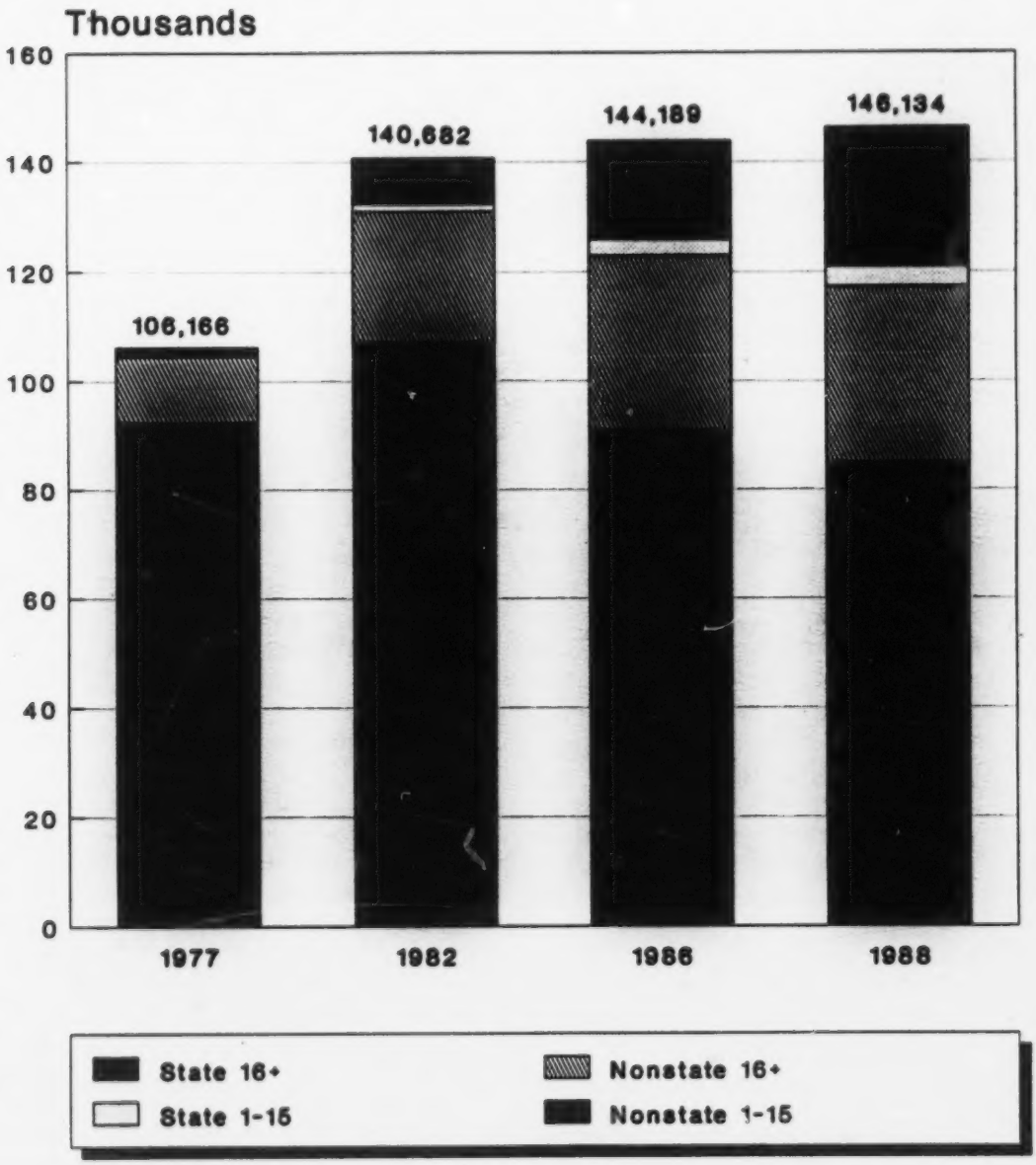


Table 6: Number and Percentage of Residents in ICF-MR Certified and Noncertified Facilities by State and Facility Size on June 30, 1988

	ICF-MR Residents			All Residents				Percentage in ICF-MR		
	1-15	16+	Total	1-15	16+	Total	% in 1-15	1-15	16+	Total
Alabama	31	1,333	1,364	777	1,443	2,220	35.0%	4.0%	92.4%	61.4%
Alaska	50	57	107	282	57	339	83.2%	17.7%	100.0%	31.6%
Arizona	0	0	0	1,829	388	2,217	82.5%	.0%	.0%	.0%
Arkansas	12	1,441	1,453	557	1,563	2,120	26.3%	2.2%	92.2%	68.5%
California	1,483	9,388	10,871	17,457	13,540	30,997	56.3%	8.5%	69.3%	35.1%
Colorado	274	875	1,149	2,151	875	3,026	71.1%	12.7%	100.0%	38.0%
Connecticut	458	956	1,414	2,799	2,196	4,995	56.0%	16.4%	43.5%	28.3%
Delaware	65	374	439	314	374	688	45.6%	20.7%	100.0%	63.8%
D.C.	410	256	666	729	277	1,006	72.5%	56.2%	92.4%	66.2%
Florida	0	3,180	3,180	3,470	4,900	8,370	41.5%	.0%	64.9%	38.0%
Georgia	0	1,913	1,913	1,351	2,267	3,618	37.3%	.0%	84.4%	52.9%
Hawaii	86e	210	296e	239	210	449	53.2%	36.0%	100.0%	65.9%
Idaho	170e	291e	461e	1,021	291	1,312	77.8%	16.7%	100.0%	35.1%
Illinois	1,792	8,554	10,346	4,149	11,700	15,849	26.2%	43.2%	73.1%	65.3%
Indiana	2,402	2,288	4,690	3,146	2,578	5,724	55.0%	76.4%	88.8%	81.9%
Iowa	59	1,781	1,840	2,165	2,252	4,417	49.0%	2.7%	79.1%	41.7%
Kansas	183	1,898	2,081	2,251	1,918	4,169	54.0%	8.1%	99.0%	49.9%
Kentucky	0	1,187	1,187	581	1,270	1,851	31.4%	.0%	93.5%	64.1%
Louisiana	1,575	4,441	6,016	1,989	4,441	6,430	30.9%	79.2%	100.0%	93.6%
Maine	243	434	677	1,451	611	2,062	70.4%	16.7%	71.0%	32.8%
Maryland	11	1,418	1,429	2,813	1,498	4,311	65.3%	.4%	94.7%	33.1%
Massachusetts	331e	3,367e	3,698e	3,762	3,430	7,192	52.3%	8.8%	98.2%	51.4%
Michigan	2,247	1,436	3,683	5,778	2,016	7,794	74.1%	38.9%	71.2%	47.3%
Minnesota	2,675	3,664	6,339	5,492	3,664	9,156	60.0%	48.7%	100.0%	69.2%
Mississippi	0	1,678	1,678	349	2,110	2,459	14.2%	.0%	79.5%	68.2%
Missouri	160	1,708	1,868	2,613	2,809	5,422	48.2%	6.1%	60.8%	34.5%
Montana	10	243	253	978	243	1,221	80.1%	1.0%	100.0%	20.7%
Nebraska	8	800	808	1,601	800	2,401	66.7%	.5%	100.0%	33.7%
Nevada	15	173	188	292	173	465	62.8%	5.1%	100.0%	40.4%
New Hampshire	60	144	204	931	144	1,075	86.6%	6.4%	100.0%	19.0%
New Jersey	0	3,815	3,815	3,022	5,304	8,326	36.3%	.0%	71.9%	45.8%
New Mexico	202	507	709	832	507	1,339	62.1%	24.3%	100.0%	52.9%
New York	6,807	10,760	17,567	16,734	10,800	27,534	60.8%	40.7%	99.6%	63.8%
North Carolina	474	2,971	3,445	1,792	3,391	5,183	34.6%	26.5%	87.6%	66.5%
North Dakota	550	338	888	1,133	383	1,516	74.7%	48.5%	88.3%	58.6%
Ohio	1,127	6,408	7,535	5,576	7,506	13,082	42.6%	20.2%	85.4%	57.6%
Oklahoma	0	3,242	3,242	804	3,242	4,046	19.9%	.0%	100.0%	80.1%
Oregon	22	1,262	1,284	1,778	1,527	3,305	53.8%	1.2%	82.6%	38.9%
Pennsylvania	815	6,549	7,364	7,485	7,536	15,021	49.8%	10.9%	86.9%	49.0%
Rhode Island	832	261	1,093	1,123	276	1,399	80.3%	74.1%	94.6%	78.1%
South Carolina	802	2,498	3,300	1,321	2,513	3,834	34.5%	60.7%	99.4%	86.1%
South Dakota	216	434	650	1,081	434	1,515	71.4%	20.0%	100.0%	42.9%
Tennessee	12	2,186	2,198	1,496	2,243	3,739	40.0%	.8%	97.5%	58.8%
Texas	1,692	10,519	12,211	2,557	10,713	13,270	19.3%	66.2%	98.2%	92.0%
Utah	45	900	945	789	948	1,737	45.4%	5.7%	94.9%	54.4%
Vermont	54	184	238	381	186	567	67.2%	14.2%	98.9%	42.0%
Virginia	136	2,882	3,018	1,152	3,056	4,208	27.4%	11.8%	94.3%	71.7%
Washington	166	2,373	2,539	3,262	2,660	5,922	55.1%	5.1%	89.2%	42.9%
West Virginia	154	263	417	540	550	1,090	49.5%	28.5%	47.8%	38.3%
Wisconsin	71	3,307	3,378	4,676	3,378	8,054	58.1%	1.5%	97.9%	41.9%
Wyoming	0	0	0	310	419	729	42.5%	.0%	.0%	.0%
U.S. Total	28,987	117,147	146,134	131,161	137,610	268,771	48.8%	22.1%	85.1%	54.4%

Columbia (61.6%), Maine (47.0%), Michigan (61.0%), Minnesota (42.2%), North Dakota (61.9%), and Rhode Island (76.1%). In contrast, 6 states actually participating in the ICF-MR program (8 states altogether) had no small ICFs-MR.

The "All Residents" columns of Table 6 present statistics on combined ICF-MR and non-ICF-MR (state and nonstate) residential facilities in the various states. These data serve as a point of comparison for facilities with ICF-MR certification. The "% in 1-15" column provides the percentage of residents in all facilities who were in small residential facilities in each state on June 30, 1988. Nationally, 48.8% of all residents of state and nonstate facilities were in "small" facilities. The "Percentage in ICF-MR" indicates the percentage of all state residents and the percentage of residents of small and large facilities specifically who were living in facilities with ICF-MR certification. It shows that 54.4% of all residents nationally were in ICF-MR facilities but that only 22.1% of all small facility residents were living in small ICFs-MR. It is also notable that a total of 28 states reported more than half their total residents in small facilities on June 30, 1988, but only 5 states (District of Columbia, Michigan, Indiana, North Dakota, and Rhode Island) reported more than half their ICF-MR residents in small facilities.

On June 30, 1988 four states had approximately two-thirds or more of their small facility residents in ICFs-MR (Indiana, 76.4%; Louisiana, 79.2%; Rhode Island, 74.1%; Texas, 66.2%). At the other extreme, 6 states using the ICF-MR program had no small ICFs-MR and 24 states had less than 10% of their small facility residential populations in ICFs-MR. Indeed, excluding the four states with more than two-thirds of their small facility population in certified facilities (and which together had 22.4% of the total small ICF-MR population nationally), only 18.0% of residents in small facilities in the remaining 47 states were in facilities with ICF-MR certification.

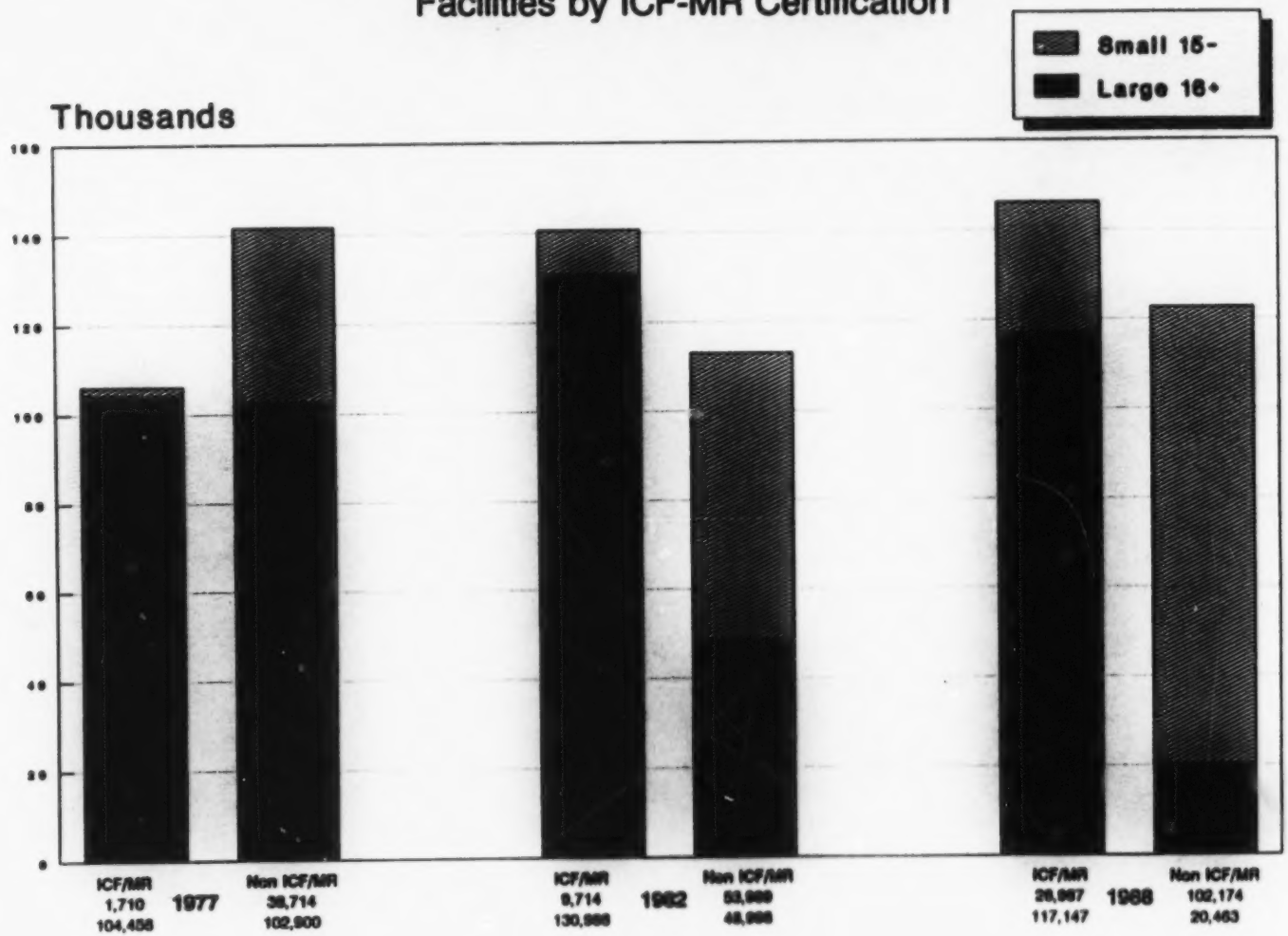
Use of small ICF-MR facilities on June 30, 1988 was dominated by nine states, each having 1,000 or more residents in small ICFs-MR, and together serving 75.2% of all small ICF-MR residents. However, this reflects much more balanced utilization than on June 30, 1977 when two states had 77% of all residents of small ICFs-MR. Further, 27 states reported 100 or more small ICF-MR residents in 1988, as compared with only 3 states serving more than 100 residents in small ICFs-MR in 1977.

Between 1982 and 1988, 36 states showed a net increase in the number of residents of small ICFs-MR and 23 states showed net increases of 100 or more. But 65% (12,527) of the total net increase (19,273) in small ICF-MR residents occurred in six states (California, Illinois, Indiana, Louisiana, Michigan and New York). Seven states showed net decreases ranging from 5 to 207 persons. Despite these clear trends toward increased numbers of persons in small ICFs-MR and participation by greater numbers of states in the option of using the ICF-MR program to fund services in small residential facilities, ICF-MR services remain predominantly concentrated in institutions in most states.

Figure 2 shows the proportion of large and small facilities among the facilities certified as ICFs-MR and facilities that were not ("non-ICF-MR") in 1977, 1982, and 1988. This figure shows the absolute and proportional growth of small facilities among both the ICFs-MR and noncertified facilities. It also shows that while the ICF-MR program continues to be primarily concentrated in institutions, there has been some shift over time to greater total and proportional use of Title XIX funding in small facilities. For example, in 1977, only 4.2% (1,710) of the total 40,400 persons in small residential settings were in ICFs-MR. In 1982, 15.2% (9,714) of 63,700 persons in small

Figure 2

Number of Residents in Large and Small Facilities by ICF-MR Certification



residential facilities were in ICFs-MR. By 1986, the percentage of all ICF-MR residents living in small residential facilities had increased to 20.2% (20,890) of 103,500 total residents, and by 1988 to 22.1% (28,987) of 131,161.

Medicaid Waiver Recipients

Although not formally a part of the ICF-MR program, the Medicaid waiver is associated with the ICF-MR program through its dedication to persons who but for the services available through the waiver program would be placed in an ICF-MR. Table 7 presents information on states' utilization of the Medicaid waiver option. It also summarizes the combined utilization of the Medicaid waiver and small ICF-MR options to provide community-based services and total utilization of ICF-MR and waiver services by the individual states on June 30, 1988.

Between enactment of the Medicaid waiver in 1981 and June 30, 1988 a total of 42 states had at one time availed themselves of the opportunity to provide home and community-based services as an alternative to ICF-MR care. On June 30, 1986, 33 states were operating approved programs for persons with mental retardation and related conditions; by June 30, 1988 there were 41. The number of waiver program participants on June 30, 1982 was estimated to be 1,605. By June 30, 1986 the number was 23,053. On June 30, 1988 there were 28,689 persons reported to be receiving Medicaid waiver services.

In comparing the numbers of waiver recipients on June 30, 1986 and June 30, 1988, 36 states had a combined increase of 10,588 waiver recipients. Three states (Arkansas, Georgia and Missouri) had received waiver approval but were serving no waiver recipients on June 30, 1988. Three states (California, Florida and New Mexico) reported a combined total of 4,952 fewer waiver recipients on June 30, 1988 than on June 30, 1986. These changes were due variously to the effects of recipient eligibility revised by the state agency, removal of certain residents/facilities from waiver coverage, or changes in reporting criteria. The net increase in waiver recipients for all states from 1986 to 1988 was 5,636 persons.

Because the waiver represents another means in addition to developing small ICF-MR residences for providing community-based care under Medicaid, it may be instructive to combine the recipients of the two programs to examine total Title XIX beneficiaries receiving institutional (16 or more residents) and community-based services for persons with mental retardation and related conditions. On June 30, 1988 there were 28,987 persons living in small ICFs-MR and 28,689 receiving Medicaid waiver services. When combined the total proportion of Medicaid service recipients (ICF-MR and waiver) being served in community-based settings was 33% of the 174,823 total Title XIX (ICF-MR and Medicaid waiver) recipients, a more favorable assessment of Title XIX utilization for community-based services when compared with the 19.8% of total ICF-MR residents residing in small ICFs-MR. Combining ICF-MR and waiver service recipients also shows 17 states to be serving the majority of their Title XIX mental retardation services recipients in community programs. The same could be said with only 4 states when only ICF-MR services were considered. While in 4 states there was still no Medicaid participation in providing community-based services for persons with mental retardation, that number was four fewer than with ICF-MR services alone.

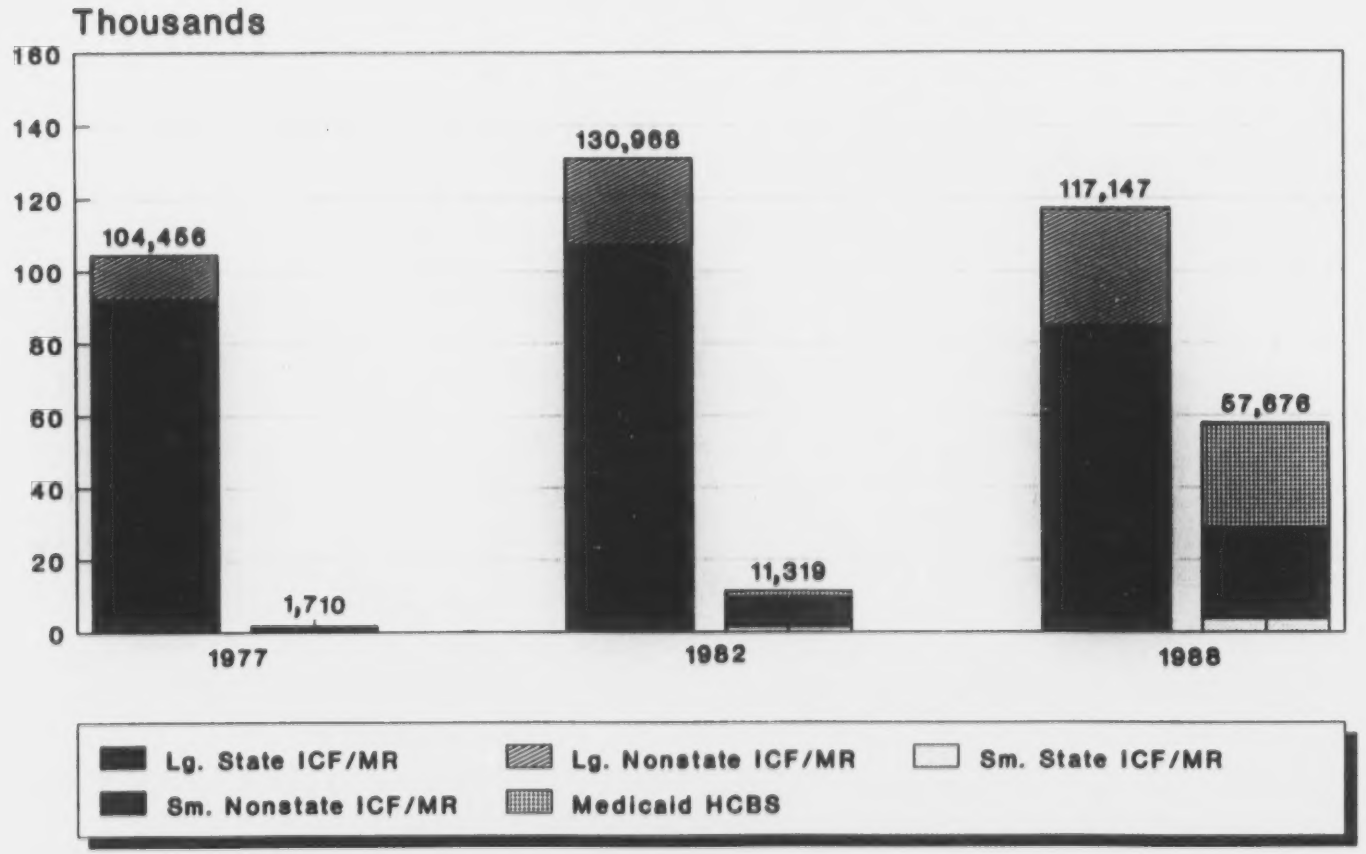
Figure 3 shows the total institutional ICF-MR service recipients (large state and large nonstate ICF-MR residents) and community recipients (small state and nonstate ICF-MR residents and waiver recipients) for 1977, 1982 and 1988. It shows the dramatic increase in community-based Title XIX service recipients from 1977 to 1988, an increase from 1,710 to 57,676. It also shows the substantial decrease in institutional recipients from 1982 to 1988, a decrease from 130,968 to 117,280.

Table 7: Beneficiaries of Medicaid Waiver and ICF-MR Services for Persons with Mental Retardation on June 30, 1988

State	State Had Waiver on 6/30/88	Number Receiving Waiver Services on 6/30/88	Total ICF-MR Residents on 6/30/88	Total Medicaid Recipients (ICF-MR + Waiver)	Total Small Community ICF-MR (1-15) Residents on 6/30/88	Total Community Medicaid (Waiver + ICF-MR 15)	% Medicaid Beneficiaries in Community on 6/30/88
Alabama	y	1,730	1,364	3,094	31	1,761	56.9%
Alaska	n	n/a	107	107	50	50	46.7%
Arizona	n	n/a	0	0	0	0	n/a
Arkansas	y	0	1,453	1,453	12	12	.8%
California	y	2,493	10,871	13,364	1,483	3,976	29.8%
Colorado	y	1,621	1,149	2,770	274	1,895	68.4%
Connecticut	y	644	1,414	2,058	458	1,102	53.5%
Delaware	y	144	439	583	65	209	35.8%
D.C.	n	n/a	666	666	410	410	61.6%
Florida	y	2,631	3,180	5,811	0	2,631	45.3%
Georgia	y	0	1,913	1,913	0	0	.0%
Hawaii	y	78	296e	374e	86e	164e	43.9%
Idaho	y	201	461e	662e	170e	371e	56.0%
Illinois	y	637	10,346	10,983	1,792	2,429	22.1%
Indiana	n	n/a	4,690	4,690	2,402	2,402	51.2%
Iowa	y	12	1,840	1,852	59	71	3.8%
Kansas	y	185	2,081	2,266	183	368	16.2%
Kentucky	y	652	1,187	1,839	0	652	35.5%
Louisiana	n	n/a	6,016	6,016	1,575	1,575	26.2%
Maine	y	450	677	1,127	243	693	61.5%
Maryland	y	716	1,429	2,145	11	727	33.9%
Massachusetts	y	593e	3,698e	4,291e	331e	924e	21.5%
Michigan	y	580	3,683	4,263	2,247	2,827	66.3%
Minnesota	y	1,896	6,339	8,235	2,675	4,571	55.5%
Mississippi	n	n/a	1,678	1,678	0	0	.0%
Missouri	y	0	1,868	1,868	160	160	8.6%
Montana	y	286	253	539	10	296	54.9%
Nebraska	y	553	808	1,361	8	561	41.2%
Nevada	y	117	188	305	15	132	43.3%
New Hampshire	y	634	204	838	60	694	82.8%
New Jersey	y	2,873	3,815	6,688	0	2,873	43.0%
New Mexico	y	134	709	843	202	336	39.9%
New York	n	n/a	17,567	17,567	6,807	6,807	38.7%
North Carolina	y	405	3,445	3,850	474	879	22.8%
North Dakota	y	824	888	1,712	550	1,374	80.3%
Ohio	y	134	7,553	7,669	1,127	1,261	16.4%
Oklahoma	y	178	3,242	3,420	0	178	5.2%
Oregon	y	968	1,284	2,252	22	990	44.0%
Pennsylvania	y	1,759	7,364	9,123	815	2,574	28.2%
Rhode Island	y	250e	1,093	1,343	832	1,082e	80.6%
South Carolina	n	n/a	3,300	3,300	802	802	24.3%
South Dakota	y	610	650	1,260	216	826	65.6%
Tennessee	y	351	2,198	2,549	12	363	14.2%
Texas	y	412	12,211	12,623	1,692	2,104	16.7%
Utah	y	1,022	945	1,967	45	1,067	54.2%
Vermont	y	248	238	486	54	302	62.1%
Virginia	n	n/a	3,018	3,018	136	136	4.5%
Washington	y	946	2,539	3,485	166	1,112	31.9%
West Virginia	y	124	417	541	154	278	51.4%
Wisconsin	y	598	3,378	3,976	71	669	16.8%
Wyoming	n	n/a	0	0	0	0	n/a
U.S. Total	Y=41	28,689	146,134	174,823	28,987	57,676	33.0%

Figure 3

Institutional and Community Recipients of
Medicaid ICF-MR and Home & Community Based Services Benefits
on June 30 of 1977, 1982, 1988



Utilization Rates for Institutional and Community Services

Statistics presented to this point have shown states to vary remarkably in the total number of persons with mental retardation and related conditions in the various types and sizes of certified and noncertified residences and receiving waiver services. The implications of such statistics can be complicated by the great variability in the size of states. Therefore, it is often useful to index such statistics by the population of states. In Table 8 this is done using states' population in 100,000s as the index.

Table 8 shows that the average number of ICF-MR residents per 100,000 of the U.S. population on June 30, 1988 was 59.5. That included 11.8 persons per 100,000 in small ICF-MR residences and 47.7 persons per 100,000 in large ICF-MR residences. Remarkable variation in utilization is evident among the states. Minnesota had the highest utilization rate nationally, with 147.2 ICF-MR residents per 100,000 of the state's population. Other states with at least twice the national average utilization were North Dakota (133.1/100,000) and Louisiana (136.5/100,000). A total of 6 other states had more than 150% of the national rate. In contrast 7 states were less than 50% of the national rate, including Arizona and Wyoming which do not participate in the program.

States with the highest utilization rates for large ICF-MR institutions included Louisiana (100.8/100,000) and Oklahoma (100.0/100,000). Seven states reported rates below 25/100,000. But by far the greatest interstate variability was evident in the small ICF-MR utilization rates. These rates ranged from 83.8 per 100,000 in Rhode Island and 82.5 in North Dakota to less than 3.0 in 20 states.

Overall Title XIX utilization tends to find similarly high interstate variability with the same states tending to be at the extremes. Nationally on June 30, 1988 there were 71.1 ICF-MR and waiver recipients per 100,000 of the nation's population. Three states were over double the national utilization rate: North Dakota (256.7/100,000), Minnesota (191.2/100,000), and South Dakota (176.7/100,000). At the other extreme, 6 states had total Title XIX utilization rates that were less than half the national rate. The very high and very low states with respect to total Title XIX utilization rates (ICF-MR and waiver) were generally the same as the very high and very low states with respect to ICF-MR utilization alone.

Utilization rates for Title XIX community-based care (waiver plus small ICF-MR) also showed great variation around the national average utilization rate of 23.5 per 100,000. Six states provided Title XIX funded community-based care to less than 1 person with mental retardation per 100,000 of the states' total population. At the other extreme ten states provided Medicaid community-based care to 54 or more persons with mental retardation per 100,000 of the state's total population.

In noting the extreme variability among states in the utilization of ICF-MR and Medicaid waiver services for persons with mental retardation, it is important to recognize that some of that variability is a reflection of the size of state residential systems in general. On June 30, 1988 states had an average total utilization of all residential placements for persons with mental retardation of 109.3 per 100,000. States varied from 40.9 placements per 100,000 in Hawaii to 227.3 in North Dakota, although only 4 states had less than half the national placement rate (Alabama, Hawaii, Nevada and Kentucky) and only North Dakota had double the national rate. In all 27 states fell in the range of 73 to 145 placements per 100,000, or the national average, 109, plus or minus 33%. Generally, then, states vary substantially in their total utilization of residential placements for persons

Table 8: Utilization Rates per 100,000 of State Population: Large and Small ICF-MR and Total Residential Facilities on June 30, 1988

State	7/1/88 State Pop. (100,000s)	ICF-MR Residents			ICF-MR (1-15) and Waiver	All ICF-MR and Waiver	ICF-MR and Non-ICF-MR		
		1-15	16+	Total			1-15	16+	Total
Alabama	41.02	.76	32.50	33.25	.76	75.43	18.94	35.18	54.12
Alaska	5.24	9.54	10.88	20.42	9.54	20.42	53.82	10.88	64.69
Arizona	34.89	.00	.00	.00	.00	.00	52.42	11.12	63.54
Arkansas	23.95	.50	60.17	60.67	.50	60.67	23.26	65.26	88.52
California	283.14	5.24	33.16	38.39	14.04	47.20	61.66	47.82	109.48
Colorado	33.01	8.30	26.51	34.81	57.41	83.91	65.16	26.51	91.67
Connecticut	32.33	14.17	29.57	43.74	34.09	63.66	86.58	67.92	154.50
Delaware	6.60	9.85	56.67	66.52	31.67	88.33	47.58	56.67	104.24
D.C.	6.17	66.45	41.49	107.94	66.45	107.94	118.15	44.89	163.0
Florida	123.35	.00	25.78	25.78	21.33	47.11	28.13	39.72	67.86
Georgia	63.42	.00	30.16	30.16	.00	30.16	21.30	35.75	57.05
Hawaii	10.98	7.83	19.13	26.96	14.94	34.06	21.77	19.13	40.89
Idaho	10.03	16.95	29.01	45.96	36.99	66.00	101.79	29.01	130.81
Illinois	116.14	15.43	73.65	89.08	20.91	94.57	35.72	100.74	136.46
Indiana	55.56	43.23	41.18	84.41	43.23	84.41	56.62	46.40	103.02
Iowa	28.34	2.08	62.84	64.93	2.51	65.35	76.39	79.46	155.86
Kansas	24.95	7.33	76.07	83.41	14.75	90.82	90.22	76.87	167.09
Kentucky	37.27	.00	31.85	31.85	17.49	49.34	15.59	34.08	49.66
Louisiana	44.08	35.73	100.75	136.48	35.73	136.48	45.12	100.75	145.87
Maine	12.05	20.17	36.02	56.18	57.51	93.53	120.41	50.71	171.12
Maryland	46.22	.24	30.68	30.92	15.73	46.41	60.86	32.41	93.27
Massachusetts	58.89	5.62	57.17	62.80	15.69	72.86	63.88	58.24	122.13
Michigan	92.40	24.32	15.54	39.86	30.60	46.14	62.53	21.82	84.35
Minnesota	43.07	62.11	85.07	147.18	106.13	191.20	127.51	85.07	212.58
Mississippi	26.20	.00	64.05	64.05	.00	64.05	13.32	80.53	93.85
Missouri	51.41	3.11	33.22	36.34	3.11	36.34	50.83	54.64	105.47
Montana	8.05	1.24	30.19	31.43	36.77	66.96	121.49	30.19	151.68
Nebraska	16.02	.50	49.94	50.44	35.02	84.96	99.94	49.94	149.88
Nevada	10.54	1.42	16.41	17.84	12.52	28.94	27.70	16.41	44.12
New Hampshire	10.85	5.53	13.27	18.80	63.96	77.24	85.81	13.27	99.08
New Jersey	77.21	.00	49.41	49.41	37.21	86.62	39.14	68.70	107.84
New Mexico	15.07	13.40	33.64	47.05	22.43	56.07	55.21	33.64	88.85
New York	179.09	38.01	60.08	98.09	38.01	98.09	93.44	60.30	153.74
North Carolina	64.89	7.30	45.79	53.09	13.55	59.33	27.62	52.26	79.87
North Dakota	6.67	82.46	50.67	133.13	206.00	256.67	169.87	57.42	227.29
Ohio	108.55	10.38	59.03	69.42	11.62	70.65	51.37	69.15	120.52
Oklahoma	32.42	.00	100.00	100.00	5.49	105.49	24.80	100.00	124.80
Oregon	27.67	.80	45.61	46.40	35.78	81.39	64.26	55.19	119.44
Pennsylvania	120.01	6.79	54.57	61.36	21.45	76.02	62.37	62.79	125.16
Rhode Island	9.93	83.79	26.28	110.07	108.96	135.25	113.09	27.79	140.89
South Carolina	34.70	23.11	71.99	95.10	23.11	95.10	38.07	72.42	110.49
South Dakota	7.13	30.29	60.87	91.16	115.85	176.72	151.61	60.87	212.48
Tennessee	48.95	.25	44.66	44.90	7.42	52.07	30.56	45.82	76.38
Texas	168.41	10.05	62.46	72.51	12.49	74.95	15.18	63.61	78.80
Utah	16.90	2.66	53.25	55.92	63.14	116.39	46.69	56.09	102.78
Vermont	5.57	9.69	33.03	42.73	54.22	87.25	68.40	33.39	101.80
Virginia	60.15	2.26	47.91	50.17	2.26	50.17	19.15	50.81	69.96
Washington	46.48	3.57	51.05	54.63	23.92	74.98	70.18	57.23	127.41
West Virginia	18.76	8.21	14.02	22.23	14.82	28.84	28.78	29.32	58.10
Wisconsin	48.55	1.46	68.12	69.58	13.78	81.89	96.31	69.58	165.89
Wyoming	4.79	.00	.00	.00	.00	.00	64.72	87.47	152.19
U.S. Total	2,458.07	11.79	47.66	59.45	23.46	71.12	53.36	55.98	109.34

with mental retardation, but their utilization of Title XIX to finance those placements varies considerably more.

Costs of ICF-MR Services

The most reliable 1988 statistics on the cost of ICF-MR services are from Braddock, Hemp, Fujiura, Bachelder and Mitchell (1989). These statistics reflect state-level budgeting for Medicaid services. In the absence of any current program or client level cost data on ICF-MR services (other than the categorical facility cost data presented in Table 11), examinations of ICF-MR cost of services are limited to statewide expenditures. Although limited in their flexibility, available statistics on total beneficiaries and expenditures provide useful data regarding the ICF-MR program. Such statistics are useful in examining longitudinal change in ICF-MR program costs as well as interstate variations in expenditures for ICF-MR services. Presented below are three general observations regarding changes over time in the cost of the ICF-MR program that derive from these statistics.

Total ICF-MR costs have been increasing rapidly. ICF-MR expenditures have been one of the fastest growing elements of the Medicaid program over the past 15 years. Between Fiscal Year 1971 and 1988 ICF-MR expenditures grew from zero (not covered) to 6.03 billion dollars. In the decade between 1976 and 1986 alone program costs increased 700%, from approximately .64 billion dollars to 5.1 billion dollars. Although the rate of growth slowed notably from Fiscal Year 1982 to Fiscal Year 1988, costs still increased 2.4 billion dollars over the period (from 3.6 billion in 1982). Before 1982 the ICF-MR program costs were pushed upward by two factors, increased number of recipients and increased costs per recipient. Since 1982 the greater costs per recipient has been by far the most significant factor in the increasing ICF-MR expenditures, accounting for about 95% of total increase, as the total number of ICF-MR residents has increased by less than 6,000.

Early cost increases were substantially due to growth in certified capacity. Much of the growth in ICF-MR expenditures since the inception of the program was attributable to the rapid expansion of state ICF-MR programs. By the end of 1975, 38 states were participating, including all large states except Indiana and New Jersey. By 1982 only 2 small states, Arizona and Wyoming, were not participating. In addition to program growth as a function of increasing numbers of states participating, participating states also increased their "certified capacity." Between Fiscal Years 1971 and 1976, the total number of persons receiving ICF-MR services grew from 0 to 89,000. Between Fiscal Years 1976 and 1988, the number of persons receiving ICF-MR services grew from 89,000 in 1976 to 140,000 in 1982 and to 146,000 on June 30, 1988. Most of the increases in cost of the ICF-MR program between 1971 and 1977 were attributable to increasing numbers of recipients.

Recent rates of increase have slowed as increases have become only a function of increasing costs per recipient. Total ICF-MR costs have been increasing in recent years almost exclusively because of increasing costs per service recipient. Because a single factor has been responsible for cost increases of recent years, cost analysis has become much more straightforward. It has also seemed less urgent, as a stable number of recipients has led to a considerably lower *rate* of growth (the average annual increase of about 400 million dollars between 1982 and 1988 was actually slightly greater than the average from 1973 to 1982). In addition to the reduction in the total growth rate of program costs, there has also been a reduction in recent years in the per resident rate of increase in the cost of ICF-MR care. While per recipient costs between 1975 and 1980 increased from $5,530 to $20,040 per year, or at an average annual rate of 29%, from 1980 to 1988 those increases were from $20,040 to $41,260, or just under 10% annually. Between 1986 and 1988, cost per ICF-MR resident increased

at more than $3,200 per year. The worst fears of geometrically increasing costs may have abated with the stabilization of the total number of ICF-MR residents, but the cost per resident continues to climb steadily. Still for the most part attention now given to the program by federal policymakers is directed toward issues of the quality, equity, and systemwide effects of the program. However on the state level cost management remains a major concern (Lakin et al., 1989).

Interstate Variations in ICF-MR Costs

Earlier in this report statistics were provided on the substantial interstate variations in the utilization of the ICF-MR option. Not surprisingly, there were also major variations in the costs of the ICF-MR programs in the various states. The variability in state ICF-MR expenditures, and federal contributions to those expenditures, is by no means predictable solely by general factors such as total ICF-MR recipients or state size. Presented below are general observations regarding the interstate variability in program costs, particularly where the variability may reflect on the quality, equity, and nationwide effects of the ICF-MR program.

Table 9 presents statistics for ICF-MR expenditures across the states in total expenditures, federal expenditures, per recipient average annual costs, per capita annual ICF-MR expenditures (ICF-MR expenditures per resident of the state), 1988 ICF-MR recipients per 100,000 of state population, each state's proportion of the total ICF-MR population, and the relative "payback" to states for ICF-MR services for each dollar of individual income tax contributed by the states to support the program. These statistics are presented for Fiscal Year 1988, the last year in which all data included in the table were available. The cost statistics provided in Table 9 derive from analyses of individual state budgets by David Braddock and his associates at the University of Illinois at Chicago (1989).

One indicator of the variation among states in ICF-MR expenditures is the average expenditure for ICF-MR service per citizen of the state. Table 9 shows the great variation with respect to these expenditures among the states. While nationally in Fiscal Year 1988 the average daily cost of ICF-MR services was $24.53 per state resident, the average varied from over twice the national average in District of Columbia ($65.43), New York ($64.63), Minnesota ($50.28), North Dakota ($56.66), Rhode Island ($56.16), and Massachusetts ($52.27) to less than half the national average in Alabama ($12.12), Georgia ($11.12), Nevada ($9.33), Hawaii ($4.87), Florida ($10.47), West Virginia ($8.58), Kentucky ($10.88), Mississippi ($10.42), and, of course, Arizona and Wyoming ($0.00). The variability in total and per citizen expenditures among states is affected by two major factors, the extent to which placements are made into ICF-MR facilities and the amount of money spent per placement.

Variations due to disproportionate placements. Variations in ICF-MR utilization rates across states have been discussed in some detail earlier in this report. These variations have an important direct effect on interstate differences in total costs and federal contributions to the total costs of residential programs in the various states. As an example of the variability, on June 30, 1988, 5 states had placed more than 80% of their total residential care population in ICF-MR certified facilities, while 14 states had 40% or less of their residents of state and nonstate residential facilities in ICFs-MR. Obviously those states with disproportionately high placement rates into ICFs-MR tended to account for disproportionate amounts of total ICF-MR expenditures.

Table 9: Summary Statistics on Expenditures for ICF-MR Care by State and U.S. for Fiscal Year 1988

State	ICF-MR Costs	Total Federal Payments for ICF-MR	ICF-MR Costs per Recipient	Total ICF-MR Expenditures per State Resident	ICF-MR Recipients per 100,000 Population	State % of Federal ICF-MR	Federal Income Tax (In Millions)	State % of Total Income Tax	State Benefit Ratio ICF-MR%/Tax%
Alabama	49,703,945	36,428,021	36,440	12.12	33.25	1.08	4,422	1.17	.92
Alaska	9,711,000	4,855,500	90,757	18.53	20.42	.14	1,088	.29	.50
Arizona	0	0	0	.00	.00	.00	4,600	1.21	.00
Arkansas	50,054,544	37,145,477	34,449	20.90	60.67	1.10	2,205	.58	1.89
California	474,662,802	237,331,401	43,663	16.76	38.39	7.02	47,690	12.58	.56
Colorado	40,895,700	20,447,850	35,592	12.39	34.81	.60	5,074	1.34	.45
Connecticut	114,786,168	57,393,084	81,178	35.50	43.74	1.70	8,736	2.30	.74
Delaware	14,417,006	7,482,426	32,841	21.84	66.52	.22	1,112	.29	.76
D.C.	40,372,000	20,186,000	60,619	65.43	107.94	.60	1,398	.37	1.61
Florida	129,141,973	71,531,739	40,611	10.47	25.78	2.12	20,901	5.51	.38
Georgia	70,527,188	45,024,557	36,867	11.12	30.16	1.33	8,597	2.27	.59
Hawaii	5,344,629	2,870,600	18,056	4.87	26.96	.08	1,517	.40	.21
Idaho	22,744,471	16,028,029	49,337	22.68	45.96	.47	901	.24	1.98
Illinois	234,661,000	117,330,500	22,681	20.21	89.08	3.47	20,194	5.33	.65
Indiana	92,507,427	58,936,482	19,724	16.65	84.41	1.74	7,595	2.00	.87
Iowa	83,595,219	52,456,000	45,432	29.50	64.93	1.55	3,229	.85	1.83
Kansas	68,842,598	38,401,114	33,081	27.59	83.41	1.12	3,492	.92	1.22
Kentucky	40,451,501	29,234,300	34,079	10.85	31.85	.86	3,933	1.04	.83
Louisiana	150,460,400	102,704,269	25,010	34.13	136.48	3.04	4,777	1.26	2.41
Maine	29,175,403	19,570,860	43,095	24.2	56.18	.58	1,489	.39	1.48
Maryland	80,806,106	40,403,053	56,547	17.48	30.92	1.19	8,710	2.30	.52
Massachusetts	307,832,416	153,916,208	83,243	52.27	62.80	4.55	12,383	3.27	1.39
Michigan	207,374,292	117,125,000	56,306	22.44	39.86	3.46	14,921	3.93	.88
Minnesota	216,549,498	116,893,419	34,161	50.28	147.18	3.46	6,309	1.66	2.08
Mississippi	27,313,120	21,754,900	16,277	10.42	64.05	.64	2,101	.55	1.17
Missouri	67,809,178	40,190,500	36,300	13.19	36.34	1.19	7,378	1.95	.61
Montana	11,542,219	8,010,300	45,621	14.34	31.43	.24	785	.21	1.13
Nebraska	28,844,241	17,228,665	35,698	18.01	50.44	.51	1,955	.52	.98
Nevada	9,837,686	4,943,437	52,328	9.33	17.84	.15	1,855	.49	.30
New Hampshire	18,824,400	9,412,200	92,276	17.35	18.80	.28	2,190	.58	.48
New Jersey	150,094,954	75,047,477	39,343	19.44	49.41	2.22	18,336	4.84	.46
New Mexico	23,582,872	16,866,470	33,262	15.65	47.05	.50	1,561	.41	1.22
New York	1,157,434,500	578,717,250	65,887	64.63	98.09	17.11	34,044	8.98	1.91
North Carolina	145,867,356	100,181,700	42,342	22.48	53.09	2.96	7,933	2.09	1.42
North Dakota	37,789,579	24,514,100	42,556	56.66	133.13	.72	744	.20	3.62
Ohio	288,358,398	170,419,813	38,269	26.56	69.42	5.04	15,332	4.04	1.25
Oklahoma	83,060,371	52,602,133	25,620	25.62	100.00	1.56	3,738	.99	1.57
Oregon	72,558,575	45,066,131	56,510	26.22	46.40	1.33	3,325	.88	1.51
Pennsylvania	349,428,073	200,397,000	47,451	29.12	61.36	5.93	17,701	4.67	1.27
Rhode Island	55,768,277	30,588,900	51,023	56.16	110.07	.90	1,580	.42	2.15
South Carolina	99,801,197	73,343,900	30,243	28.76	95.10	2.17	3,651	.96	2.26
South Dakota	20,518,961	14,451,504	31,568	28.78	91.16	.43	679	.18	2.37
Tennessee	77,564,261	54,791,394	35,289	15.85	44.90	1.62	6,072	1.60	1.01
Texas	365,748,009	208,147,192	29,952	21.72	72.51	6.16	25,078	6.61	.93
Utah	34,253,628	25,255,200	36,247	20.27	55.92	.75	1,633	.43	1.74
Vermont	15,907,897	10,535,800	66,840	28.56	42.73	.31	728	.19	1.64
Virginia	109,091,936	56,007,800	36,147	18.14	50.17	1.66	9,852	2.60	.64
Washington	112,872,686	60,059,556	44,456	24.28	54.63	1.78	7,012	1.85	.96
West Virginia	16,090,632	12,042,229	38,587	8.58	22.23	.36	1,846	.49	.73
Wisconsin	114,470,170	67,514,506	33,887	23.58	69.58	2.00	6,168	1.63	1.22
Wyoming	0	0	0	.00	.00	.00	659	.17	.00
U.S. Total	6,029,050,461	3,381,385,946	41,257	24.53	59.45	100.00	379,209	100.03	1.00

Variations due to differences in per recipient cost. Placement rates are not the only factor accounting for interstate differences in ICF-MR expenditures. Obviously the average number of dollars expended per ICF-MR resident is also a key factor. Table 9 also shows the enormous variations among states in the average per resident cost of ICF-MR care. The national average cost of ICF-MR care per recipient in Fiscal Year 1988 (total ICF-MR expenditures in the year divided by total recipients) was $41,257 per year. Among the states with the highest per recipient costs in 1988 were New Hampshire ($92,276 per person per year), Alaska ($90,787), Massachusetts ($83,243), and Connecticut ($81,178). Among the states with the lowest per recipient costs were Mississippi ($16,277), Hawaii ($18,056), and Indiana ($19,724). The effects of relatively high per resident costs are straightforward. For example, Massachusetts, New Hampshire, Connecticut, and Alaska had 3.7% of all ICF-MR residents on June 30, 1988, but accounted for 7.5% of total FY 1988 ICF-MR expenditures. Obviously, when a state is both a high user of the ICF-MR option and has high cost per recipient, its total expenditures become particularly notable. New York stands out in this regard. Although New York had only 7.3% of the total U.S. population and 12.0% of the ICF-MR population on June 30, 1988, in FY 1988 it accounted for 19.2% of all ICF-MR expenditures.

Variations in state financial benefit. It was noted in the general description of the ICF-MR program that, like all Medicaid programs, the federal government shares the costs of ICF-MR services with the states as a function of the state per capita income relative to national per capita income. Relatively rich states share total costs on an equal basis with the federal government, relatively poor states may have federal involvement in financing Medicaid services up to 83%. (Mississippi's 79.7% was the highest federal share in 1988.) It is often presumed, therefore, that the extent to which states benefit from ICF-MR program participation tends to be related to their general need for assistance as reflected in the federal Medicaid cost share ratio. However, because states vary considerably in their ICF-MR utilization rates, in the proportions of their licensed facilities participating in the ICF-MR program, and in their costs per recipient, some deviation should be expected between total benefit in federal dollars from the ICF-MR program and the proportion of total ICF-MR costs reimbursed by the federal government.

To assess the extent of variance a "state benefit ratio" was computed. The state benefit ratio in Table 9 represents a ratio of federal ICF-MR reimbursements paid to each state for each dollar contributed to the program through personal income tax. Obviously such an index masks certain realities: first, revenues for the Medicaid program do not come exclusively through personal income tax; second, expenditures for federal programs in recent years have not been equal to the revenues generated for those programs (i.e., the United States has substantially greater expenditures than revenues). Despite the oversimplifications, such an index is one way of assessing the balance between state contributions to the federal government for the ICF-MR program and federal reimbursements back to the states for ICF-MR services, and the extent to which imbalances are of an intended nature. Table 9 shows that in Fiscal Year 1988, North Dakota got back over three dollars in federal reimbursements for every dollar contributed, and five other states exceeded two dollars received for each dollar paid (Louisiana, $2.46; Minnesota, $2.08; Rhode Island, $2.65; South Carolina, $2.26; and South Dakota, $2.37). In contrast six states got back less than $.50 in reimbursements for every dollar contributed (Colorado, $.45; Florida, $.38; Hawaii, $.21; Nevada, $.49; and New Jersey, $.46).

Of the 25 states showing a favorable "State Benefit Ratio" (state's % of total Federal ICF-MR reimbursements divided by state's % of total Federal income tax payments), seven of the eleven poorest states were included, while only three of the eleven richest states were present. Therefore, while differential ICF-MR utilization and average costs may cause a number of poorer states (e.g.,

Georgia, Kentucky, West Virginia) to be subsidizers of ICF-MR services in relatively wealthy states (e.g., Minnesota, New York, Rhode Island), the highly favorable Medicaid federal-state cost share for the poorer states does establish at least a tendency for them to receive more federal funds from ICF-MR reimbursements than they contribute to them.

Nursing Home Residents with Mental Retardation

Table 10 presents the number of people with mental retardation and related conditions reported by states to be in nursing facilities, other than ones specifically licensed for persons with mental retardation and related conditions. This was the first year that statistics were obtained from all states on nursing home residents with mental retardation. The primary factor in states' improved capacity to report an actual or estimated count was the new requirement under the Omnibus Budget Reconciliation Act of 1987 (OBRA-87), that states screen nursing home residents with mental handicaps for the appropriateness of their placement. States were required to submit an "Alternative Disposition Plan" to the U.S. Department of Health and Human Services regarding the findings of those screenings. Most states submitted that plan in December 1988 and the findings of those screening activities were the statistics reported by most states for their nursing home residents with mental retardation, despite the request that the count be for June 30, 1988 or the closest possible date.

In all, states indicated 42,679 persons with mental retardation to be in nursing homes. This statistic is reasonably consistent with the 1987 National Medical Expenditure Survey estimate of 45,261 persons with a primary diagnosis of mental retardation in nursing homes (see Table 23). Nationwide the total reported number of persons with mental retardation in nursing homes was 24.4% of the total number receiving ICF-MR and Medicaid waiver services. In 10 states the reported number of nursing home residents with mental retardation was at least 50% of the number of people receiving ICF-MR and waiver services. Nationwide, the reported number of nursing home residents with mental retardation and related conditions equalled 15.9% of the nation's total population of persons in state licensed or operated mental retardation facilities. Three states (Alabama, Georgia and Virginia) reported nursing home residents equal to 50% or more of mental retardation facility residents.

Table 10: Persons with Mental Retardation and Related Conditions in Nursing Facilities on June 30, 1988[1]

State	Nursing Home (NH) Residents with MR[2]	Total ICF-MR/ Waiver Recipients	NH Residents as % of ICF-MR/Waiver Recipients	Total MR Residents	NH Residents as % of Total MR Residents
Alabama	1,650e	3,094	53.3%	2,220	74.3%
Alaska	30e	107	28.0%	339	8.8%
Arizona	300e	0	n/a	2,217	13.5%
Arkansas	800e	1,453	55.1%	2,120	37.7%
California	869	13,364	6.5%	30,997	2.8%
Colorado	482e	2,770	17.4%	3,026	15.9%
Connecticut	622	2,058	30.2%	4,995	12.5%
Delaware	305	583	52.3%	688	44.3%
D.C.	85e	666	12.8%	1,006	8.4%
Florida	143	5,811	2.5%	8,370	1.7%
Georgia	2,050e	1,913	107.2%	3,618	56.7%
Hawaii	66	374e	17.6%	449	14.7%
Idaho	75e	662e	11.3%	1,312	5.7%
Illinois	3,000e	10,983	27.3%	15,849	18.9%
Indiana	2,500	4,690	53.3%	5,724	43.7%
Iowa	532e	1,852	28.7%	4,417	12.0%
Kansas	60	2,266	2.6%	4,169	1.4%
Kentucky	487	1,839	26.5%	1,851	26.3%
Louisiana	1,200	6,016	19.9%	6,430	18.7%
Maine	168	1,127	14.9%	2,062	8.1%
Maryland	300e	2,145	14.0%	4,311	7.0%
Massachusetts	192e	4,291	4.5%	7,192	2.7%
Michigan	2,200e	4,263e	51.6%	7,794	28.2%
Minnesota	961	8,235	11.7%	9,156	10.5%
Mississippi	280e	1,678	16.7%	2,459	11.4%
Missouri	468	1,868	25.1%	5,422	8.6%
Montana	300e	539	55.7%	1,221	24.6%
Nebraska	353	1,361	25.9%	2,401	14.7%
Nevada	61	305	20.0%	465	13.1%
New Hampshire	25e	838	3.0%	1,075	2.3%
New Jersey	2,479	6,688	37.1%	8,326	29.8%
New Mexico	86	843	10.2%	1,339	6.4%
New York	1,323	17,567	7.5%	27,534	4.8%
North Carolina	316	3,850	8.2%	5,183	6.1%
North Dakota	289	1,712	16.9%	1,516	19.1%
Ohio	4,756	7,669	62.0%	13,082	36.4%
Oklahoma	1,400e	3,420	40.9%	4,046	34.6%
Oregon	285	2,252	12.7%	3,305	8.6%
Pennsylvania	300e	9,123	3.3%	15,021	2.0%
Rhode Island	225	1,343	16.8%	1,399	16.1%
South Carolina	49	3,300	1.5%	3,834	1.3%
South Dakota	142	1,260e	11.3%	1,515	9.4%
Tennessee	930e	2,549	36.5%	3,739	24.9%
Texas	3,500e	12,623	27.7%	13,270	26.4%
Utah	389	1,967	19.8%	1,737	22.4%
Vermont	125e	486	25.7%	567	22.0%
Virginia	2,300e	3,018	76.2%	4,208	54.7%
Washington	573	3,485	16.4%	5,922	9.7%
West Virginia	383	541	70.8%	1,090	35.1%
Wisconsin	2,200	3,976	55.3%	8,054	27.3%
Wyoming	65e	0	n/a	729	8.9%
U.S. Total	42,679	174,823	24.4%	268,771	15.9%

Note. [1]Data provided by many states were those submitted in their December 1988 Alternative Disposition Plans.
[2]In some states this statistic includes people placed in nursing homes under the sponsorship of the state MR/DD agency as well as persons placed by families or other agencies. For example, Alabama's estimate of 1,650 total nursing home residents includes an estimated 155 individuals under the sponsorship of the Department of MH/MR.

PART III: CHARACTERISTICS OF RESIDENTS OF ICFs-MR IN 1987

Part III of this report uses statistics obtained from the Institutional Population Component of the 1987 National Medical Expenditure Survey (NMES) to describe the characteristics of residents of ICF-MR certified facilities. It also provides for comparative purposes descriptive statistics on residents in facilities that are not ICF-MR certified. The National Medical Expenditure Survey included a sample of 3,618 persons in 691 facilities primarily serving people with mental retardation and related conditions. Of these 2,303 sample members were residents of 296 sampled facilities with ICF-MR certification. The Institutional Population Component of the 1987 National Medical Expenditure Survey provided considerable detailed information on the demographic, diagnostic, functional and other characteristics of persons in publicly-operated residential facilities. These data provide a description of many important characteristics of the individuals enumerated in Part II of this report.

Methodology

A separate "Mental Retardation Facilities" sample was developed for the Institutional Population Component of the 1987 National Medical Expenditure Survey. It was based on a three-stage probability design. The three stages included: 1) development of a universe of all facilities meeting the definition of a "mental retardation facility"; 2) selection of a controlled sample of facilities from that universe; and 3) selection of a random sample of residents of those facilities. Details of the sampling strategy are reported in Edwards and Edwards (1989).

Universe of Facilities

The universe of facilities serving as the sample frame for the National Medical Expenditure Survey was the 1986 Inventory of Long-Term Care Places (ILTCP) (Sirrocco, 1989). The ILTCP was carried out to identify facilities primarily serving persons with mental retardation, verify eligibility as a "mental retardation facility," and to provide statistics on population and administrative characteristics of facilities on which the sample stratification, selection, and eventual facility weighting for the Institutional Population Component of NMES could be based. The ILTCP defined mental retardation facilities as formally state licensed or contracted [including state-operated] living quarters which provided 24-hour, 7-days-a-week responsibility for room, board and supervision primarily to persons with mental retardation who were not relatives.

Construction of the registry. Prior to conducting the actual "inventory" stage of the ILTCP, a list of facilities potentially meeting the definition of a mental retardation facility was constructed using a national census of residential facilities for persons with mental retardation conducted by the Center for Residential and Community Services at the University of Minnesota (Hauber, Bruininks, Hill, Lakin, & White, 1984). To that registry of 15,633 facilities were added all other facilities identified by states and "relevant associations" as operating in late 1985, but which were not included in the 1982 census survey.

Surveying and screening the registry (the ILTCP). The ILTCP was a simultaneous survey of the mental retardation facilities identified as described above, as well as nursing and related care homes identified in a similar manner using the National Center on Health Statistics' 1982 National Master Facility Inventory as the base registry. The Bureau of the Census carried out the actual

ILTCP survey of 56,728 total facilities on the registry. Of these 5,808 could not be surveyed because of insufficient information, inability to locate, or eventual dropping for nonresponse. There were 174 direct refusals. Another 5,500 places were not operating as residential facilities at the time of the survey, or were not providing residential services at the specific address (e.g., were home offices for multiple facilities).

The ILTCP survey outcomes were used by the National Center for Health Services Research (NCHSR) to evaluate all 56,728 facilities in the registry for their status as a mental retardation facility. According to a set of hierarchical decision rules, the process eliminated from the mental retardation facility universe facilities that were determined to be nursing or related care homes, duplicate addresses or facilities that were otherwise out-of-scope (no current residents with mental retardation, administrative offices, not 24-hour residential programs, etc.). In all 15,351 "mental retardation facilities" were identified in the 1986 ILTCP, 1,347 of which also met the definition of nursing and related care home (Potter, Cohen, & Mueller, 1987).

Facility Sample

In addition to its use as determining the current status of mental retardation facilities and nursing and related care facilities, the ILTCP gathered the basic data needed to structure the facility sample. However, prior to selecting the mental retardation facility sample from the ILTCP, it became evident that the ILTCP contained fewer of the smaller, non-ICF-MR residential settings than were identified in the 1982 mental retardation facility census (Hauber et al., 1984) and far fewer than were reported by state mental retardation/developmental disabilities agencies in 1986 (Lakin, Hill, White, Bruininks, & Wright, 1988). Because the underidentification appeared most notable among the smallest facilities, it was decided to exclude all settings of 2 or fewer residents from the ILTCP for the purposes of drawing a sample for the National Medical Expenditure Survey, thus eliminating facilities of that size from the Institutional Population Component of NMES. This, of course, did not affect estimates of persons in ICFs-MR since they must by regulation have at least 4 residents.

The remaining identified mental retardation facilities were then stratified by their status as community-based ICFs-MR (4-15 beds), noncertified community-based facilities (3-15 beds), or facilities with 16 or more residents. Within these strata facilities were further grouped by census region, ICF-MR certification, type of operation, number of "beds," state and zip code. Facilities were then sampled with probabilities of selection proportional to their size, but with some clustered subsampling of similarly grouped facilities to reduce field costs of the interviewing. A total of 691 separate mental retardation facilities were selected in the sample, 296 of which were ICF-MR certified and 395 of which were not ICF-MR certified.

Selection of Sample Members

A current resident sample was selected in each facility from a listing of all persons residing in the facility on January 1, 1987. Sampling was random, with a predetermined number of sample members drawn from each facility to insure that representation for residents within strata was equal to their proportion of all residents in the sample frame. In all 3,618 residents of mental retardation facilities were sampled.

Response Rates

To obtain the final yield of 691 mental retardation facilities, 730 eligible facilities were sampled from the ILTCP. Of these facilities 691 responded to the facility questionnaire, with 31 refusals and 2 other nonrespondents. To obtain the final yield of 3,618 current residents, 3,738 eligible residents were sampled. There were 29 refusals by facility officials to provide individual interviews, 86 refusals by individuals or guardians other than facility officials, and 7 other nonresponses. Thus, the overall response rates for selected facilities (94.7%) and for selected residents within facilities agreeing to participate (96.8%) were quite high.

Data Limitations

Originally, the mental retardation facility sample frame was intended to include all types and sizes of mental retardation facilities meeting the operational definition. However, as noted in a NCHSR staff paper on the NMES sample frame:

> A final comparison of the 1986 ILTCP MR universe to the 1982 NCRF [National Census of Residential Facilities] universe (Hauber et al, 1984) suggested undercoverage of one and two bed MR facilities by the ILTCP. A likely explanation is that the very small MR facilities are more likely to close or move than large facilities. This jeopardized completeness of the frame, so one and two bed MR's were deleted at the end of the eligibility determination process (Potter, Cohen & Mueller, 1987, p. 826).

Underidentification of persons in small facilities was clearly reflected in the differences between ILTCP and NMES estimates of the total population of persons with mental retardation and related conditions in mental retardation facilities (about 218,000) and the 244,000 identified in the 1982 census (Hauber et al., 1984) and the 252,000 reported by states in 1986 (Lakin et al., 1988). But the underestimation appears largely confined to facilities of 6 and fewer residents which did not have ICF-MR certification. The magnitude of the undercount appears on the order of 25,000-30,000 small facility residents (including facilities with 1 or 2 residents), or in the neighborhood of 30% of all small facility residents (Lakin, Hill, Chen, & Stephens, 1989). These limitations likely affect the accuracy of the data presented on "non-ICF-MR" and "all facilities." The limitations described appear to have had little, if any, effect on the ICF-MR facility and resident estimates.

Table 11 presents summary statistics on facility groupings by ICF-MR/non-ICF-MR ("not certified") status. The NMES estimates of populations of both large and small ICF-MR facilities are quite similar to the statistics reported by states at the time the NMES sample frame was being developed (Lakin et al., 1987). States reported that on June 30, 1986 they had 20,890 residents with mental retardation and related conditions in small ICFs-MR. The NMES estimated 21,077. For the same date, states reported 122,925 persons with mental retardation and related conditions in large ICFs-MR. The NMES estimated 118,084. As noted before, noncertified facilities appear substantially underestimated in NMES when compared to state reports, with almost all of the discrepancy being in the smaller (15 or fewer resident) facilities.

In general then the population statistics obtained on ICF-MR facilities and residents from NMES appear to be well within normal ranges of sampling error. Population estimates on non-ICF-MR and total facilities and their residents suffer from an incomplete sample frame. Because of this descriptive statistics such as percentages and averages are generally used instead of numerical

estimates to describe the populations of ICF-MR certified, non-ICF-MR ("not certified"), and total facilities.

Table 11: Facilities, Set-up Beds and Residents by ICF-MR Certification Status

	ICF-MR Certified			Not Certified			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
N of facility	3,330	904	4,235	7,724	1,372	9,095	11,054	2,276	13,330
Set up beds	24,083	130,580	154,663	49,784	58,964	108,748	73,867	189,544	263,411
Current res	21,420	123,089	144,509	48,062	47,048	95,109	69,481	170,137	239,619
MR/RC res	21,077	118,084	139,161	43,859	35,613	79,472	64,936	153,697	218,633

Notes. Number of facilities are weighted estimates based on the facility questionnaire data. Facility size is based upon the number of set up beds in reporting unit. The total facility may be larger than the reporting unit, although this is presumably seldom the case. The number of residents is commonly less than the number of set up beds. National estimates of current residents from the Baseline (resident) Questionnaire and "set up beds" from the Facility Questionnaire indicate the former to be 91.0% of the latter. Number of current residents include residents who do not have mental retardation (MR) or a related condition (RC). Number of MR/RC residents (mental retardation and related conditions) are weighted estimates from the resident baseline questionnaire. All references to MR mean MR/RC. Based on analysis of their size and operation, facilities with missing data for "ICF-MR" were assumed to be not certified. Because data are weighted and rounded to nearest whole number, some totals may not equal 100%.

Facility Administrative Data

Table 12 presents basic administrative statistics for ICF-MR and noncertified facilities by type of operation and facility size. The statistics presented on facility capacity, current residents and certified capacity have the limitations discussed above.

Proportion of Capacity Occupied

Data from the 1987 National Medical Expenditure Survey (NMES) indicate occupancy of mental retardation facilities to be 90.2% of the maintained capacity of facilities. ICF-MR certified facilities had an occupancy of 92.0%. The noncertified facilities were 87.5% occupied. Small ICFs-MR reported a 89.0% occupancy rate; large ICFs-MR an 94% occupancy. The lowest occupancy rates were among the large private noncertified facilities (78.7%).

Proportion of Residents with Mental Retardation or Related Conditions

Based on NMES data, 91.2% of the residents of mental retardation facilities were persons with mental retardation or related conditions. ICF-MR certified facilities had a much higher proportion of their total population made up of persons with mental retardation or related conditions (96.3%) than did noncertified facilities (83.6%). In general, private for profit facilities were most likely to have residents who were reported not to have mental retardation or related conditions (23.7% of all residents), but among the for profit ICF-MR certified facilities 98.7% of residents were reported to have mental retardation or related conditions. Among noncertified, private for profit facilities, an estimated 32.3% of residents did not have mental retardation or related conditions.

Medicaid Certified Capacity

According to the NMES, mental retardation facilities nationwide had a total of 156,735 "beds" certified for Medicaid participation. The Medicaid capacity within mental retardation facilities was overwhelmingly concentrated in the ICF-MR program (98.7%). The estimates of Skilled Nursing Facility (SNF) and Intermediate Care Facility (ICF) capacities (584 and 1,489 total "beds" respectively) were based on so few sampled facilities that they cannot be considered reliable estimates of SNF and ICF certification of units in mental retardation facilities.

The Medicaid certified capacity of mental retardation facilities was indicated to be highly concentrated in large facilities. About 84% of total (ICF-MR, ICF and SNF) Medicaid certified capacity was estimated to be in large facilities, as was 84% of ICF-MR certified capacity alone. Generally speaking, the smaller the facility grouping the less likely it was to have its residential capacity certified for Medicaid participation. For example, facilities with 800 or more residents had 100% of their capacity Medicaid certified; those with 300-799 residents were 96.6% certified; those with 76-299 residents were 66.9% certified; and facilities with 16-75 residents were 31.3% certified. The undercounting of small (less than 16 residents) facilities is confined almost exclusively to small, noncertified facilities which greatly affects estimated proportion of small facility capacity certified. While the NMES estimated that 32.6% of small facility capacity was ICF-MR certified, and that 32.5% of small facility residents with mental retardation and related conditions were in ICF-MR units, state reports of small facilities and small facilities with ICF-MR certifications for 1987 indicated 19.8% to be ICF-MR certified (Lakin et al., 1989). Given underrepresentation of small facilities in the NMES, the 19.8% statistic seems a more accurate reflection of participation of small facilities in the ICF-MR program.

Direct Care Personnel

Substantial differences were found among facilities in their ratios of direct care personnel to their total current "set up beds." Generally, NMES indicated that there were now more people providing direct care nationally than are receiving it (1.06 direct care staff:1 resident). But given 168 hours in a week and the prevailing 40 hour work week, this would translate to an average resident to direct care staff ratio of about 4 to 1 at any one time. Ratios of staff to residents were much higher in ICF-MR certified facilities (1.33:1) than among non-ICFs-MR (.66:1). Small ICFs-MR had much lower staff to resident ratios than did large ICFs-MR (.92:1 and 1.41:1, respectively). Among the small ICFs-MR non-government facilities had lower staff to resident ratios than the public facilities (.90:1 and 1.07:1, respectively). Small for profit facilities had the lowest staff to resident ratios for both certified and noncertified facilities (.60 and .44 staff members per resident, respectively). One factor in these lower ratios was the fact that in many of the smaller proprietary facilities the owner/operators lived in the "facility" and were providing care and supervision for considerably more hours than was indicated by their being reported as a single full-time direct care position. One factor in the generally higher ratios in ICFs-MR was, as will be described later, that the residents of these facilities tended to have more extensive needs for care and supervision than did residents of non-ICFs-MR.

Table 12: Basic Administrative Data by ICF-MR Certification Status and Facility Operation

	Facility Operation											
	Private for Profit			Private NonProfit			Public			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
ICF-MR Certified												
Total maintained capacity	7,188	20,779	27,967	13,394	11,796	25,189	3,501	100,375	103,876	24,083	130,580	157,033
Total current residents	6,264	18,409	24,673	12,153	12,703	24,856	3,003	89,607	92,610	21,420	123,089	144,509
Total MR/RC residents	6,128	18,228	24,356	11,946	12,302	24,248	3,004	87,554	90,558	21,077	118,084	139,161
Total ICF-MR beds	7,188	18,409	25,598	13,393	11,796	25,189	3,501	100,375	103,876	24,083	123,089	154,663
Direct care per bed	.60	1.02	.91	1.06	.91	.99	1.07	1.54	1.53	.92	1.41	1.33
Per diems by range												
$1-$30	29.0%	13.5	17.7	11.3	23.4	17.1	7.7	0.0	0.2	16.5	4.0	5.9
31-55	21.3	51.5	43.3	15.1	20.8	17.9	0.0	0.8	0.8	15.1	10.1	10.8
56-80	38.7	27.6	30.6	37.5	20.1	29.1	20.1	12.5	12.7	35.6	15.4	18.4
81-105	0.0	7.4	5.4	21.2	15.7	18.5	35.5	23.2	23.6	16.3	20.2	19.6
106+	11.1	0.0	3.0	14.9	20.1	17.4	36.7	63.5	62.8	16.5	50.3	45.4
Not ICF-MR Certified												
Total maintained capacity	22,830	26,786	51,616	23,897	25,554	47,661	4,847	4,624	9,461	49,784	56,964	106,748
Total current residents	19,365	23,896	43,261	23,897	18,854	42,751	4,800	4,297	9,096	48,062	47,048	95,109
Total MR/RC residents	15,584	13,691	29,275	23,644	17,935	41,579	4,631	3,987	8,618	43,859	35,613	79,472
Total SNF/ICF beds	427	745	1,173	0	0	0	649	250	899	1,076	995	2,072
Direct care	.44	.46	.45	.76	.88	.83	.90	.97	.94	.63	.69	.66
Per diems by range												
$1-$30	76.4%	67.5	71.1	42.6	26.3	34.2	22.9	13.3	17.6	55.7	45.0	49.5
31-55	5.5	16.7	12.2	30.2	30.3	30.2	30.8	0.0	13.9	19.4	21.8	20.8
56-80	5.4	8.7	7.4	13.9	19.5	17.2	0.4	11.3	6.4	8.9	14.0	11.9
81-105	5.0	3.6	4.2	4.0	7.8	6.3	19.7	14.3	16.7	5.8	8.4	6.2
106+	7.8	3.5	5.2	9.3	14.1	12.1	26.1	61.1	45.3	10.1	12.8	11.7
All Facilities												
Total maintained capacity	30,018	47,196	77,214	35,502	37,349	72,851	8,348	104,999	113,347	73,867	189,544	265,781
Total current residents	25,629	44,676	70,304	36,050	31,557	67,607	7,803	93,904	101,707	69,481	170,137	239,619
Total MR/RC residents	21,712	31,919	53,632	35,590	30,237	65,827	7,633	91,541	99,174	64,936	153,697	218,633
Total Medicaid beds	7,615	19,154	26,769	13,394	11,796	25,189	4,150	100,624	104,775	25,160	131,575	156,735
Total ICF-MR beds	7,188	18,409	25,598	13,394	11,796	25,189	3,501	100,375	103,876	24,083	130,580	154,663
Direct care	.48	.69	.61	.87	.89	.88	.97	1.51	1.48	.72	1.18	1.06
Per diems by range												
$1-$30	63.3%	45.3	51.7	30.7	26.9	28.6	16.3	0.6	1.5	42.2	17.1	23.5
31-55	9.9	31.0	23.5	24.4	27.6	26.2	17.5	0.8	1.8	17.9	13.8	14.8
56-80	14.6	16.5	15.8	22.9	19.7	21.1	8.9	12.4	12.2	18.1	14.9	15.7
81-105	3.6	5.2	4.6	10.6	10.1	10.3	26.5	22.8	23.0	9.4	15.8	14.2
106+	8.7	2.1	4.4	11.4	15.8	13.8	30.7	63.4	61.4	12.3	38.4	31.8

Notes. Total maintained capacity is number of set up beds in reporting unit, estimated from weighted data on facility questionnaire. Total current residents and residents with MR/RC are weighted estimates from resident baseline questionnaire. Most facilities with Medicaid certification (78.4%) are indicated to be 100% certified. For other facilities with Medicaid certification, total ICF, ICF-MR, and SNF beds are estimated to be the number of set up beds multiplied by the midpoint of multiple categories (e.g., 0-10% = 5%) of the recoded variables "percent of beds certified." Facilities with missing bed certification data but which are ICF-MR certified are assumed to be 100% ICF-MR. Per diems by range are the estimated percentage of residents in each facility category living in facilities in each per diem range. Facility size weights are "set up beds." Direct care personnel estimates are expressed as number of FTE direct care staff (licensed nurses, nurse aids/orderlies, recreation/activity staff, and "all other care staff") per set up bed. "Part time" assumed to equal 50% FTE. Data are weighted to represent correct proportions of set up beds (approximately equal to the number of residents). Row and column totals may not be equal because of differences in missing data across cells.

Per Diem Costs

A major limitation of the NMES facility data was that costs were coded into 5 broad cost categories from continuous per day cost statistics that were originally gathered. The categories created from the NMES data and the weighted proportion of residents within the facilities of each range were: a) $30 or less per day (23.5% of all facilities in the sample), b) $31-$55 (14.8%), c) $56-$80 (15.6%), d) $81-$105 (14.2%), and e) $106 or more per day (31.8%). Based on other surveys (Hill, Lakin, Bruininks, Amado, Anderson, & Copher, 1989; White, Lakin, Hill, Wright, & Bruininks, 1988), facility costs generally range from $15 to well over $300 per day, so that the extreme data reduction in the NMES data files greatly decreased the usefulness of the facility cost statistics.

ICF-MR certified facilities, regardless of operator or size, were much less likely to be found in the lower cost ranges (e.g., $55 per day or less) than noncertified facilities. Among private for profit facilities, 83% of residents in noncertified facilities were in places with a daily cost of $55 or less as compared with 51% of residents of ICFs-MR. Among nonprofit facilities, 64% of residents in noncertified facilities and 35% of those in ICFs-MR were in places with a cost of $55 a day or less. Among government operated facilities, 21% of noncertified facility residents were in places costing $55 or less per day, as compared with an estimated 1% of persons in public ICFs-MR. Conversely, an estimated 65% of public and private ICF-MR residents were in places that cost $81 or more per day as compared with 18% of persons in noncertified facilities. An estimated 72.2% of residents in small, government ICFs-MR were in facilities costing $81 per day or more. This compared with 27.6% of residents of small private ICFs-MR and 15.9% of the sampled small facilities that were not ICF-MR certified. These cost variations were likely due primarily to differences in direct care and professional staffing intensities and pay scales, since personnel costs make up the bulk of the costs of operating residential facilities.

Resident Movement

Table 13 presents basic resident movement statistics for calendar year 1986 for ICF-MR and noncertified facilities by type of operation and size. Movement is expressed as a percentage of the "current residents." Movement data were based on Facility Questionnaire responses, but included only facilities open for all of 1986. This had the effect of underestimating admissions to small facilities which generally have very high occupancy and which as a class tend to increase their total resident population by the creation of new facilities rather than increasing the number of people in existing facilities. Again, underrepresentation of small facilities may have affected the estimated rates for the small noncertified facilities.

Admission/Discharge Rates

Admission and discharge rates were generally higher among facilities without ICF-MR certification than among the ICFs-MR (16.2% vs. 9.0% for admissions and 14.0% vs. 9.9% for discharges). In general rates tended to be more similar between small and large facilities of the small certification types (ICF-MR or non-ICF-MR) than between facilities of the same general size category (15- residents or 16+ residents), but of different certification status. However, the smallest facilities (3-6 residents) were the most active in admissions and discharges during 1986 irrespective of ICF-MR status. They reported admissions in 1986 equal to 18.9% of their residential population and discharges equal to 14.2% of their residential population. Specific

admission/discharge rates for 6 and fewer resident ICFs-MR were 17.7 and 11.3, as compared with 19.4 and 15.6 for the noncertified facilities with 6 or fewer residents. Private for profit facilities had the highest admission and discharge rates for both ICF-MR and non-ICF-MR facilities, with the greatest movement reported among facilities with 15 or fewer residents. While providing important information to evaluate service trends, the NMES baseline data do not include reasons for residents' movement.

Deaths

The estimated national death rate in residential facilities serving persons with mental retardation was 1.4% of the resident population. This included an estimated rate of 1.4% in ICF-MR facilities and 1.5% in noncertified facilities. These two estimates do not represent statistically significant differences. The estimated national death rate of 1.4% compares with 1.2% obtained in the 1982 National Census of Residential Facilities (Lakin, Hill, & Bruininks, 1985).

Table 13: Basic Resident Movement by ICF-MR Certification and Facility Operation

	Facility Operation											
	Private for Profit			Private Non-Profit			Public			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
ICF-MR Certified												
Total current residents	6,264	20,779	27,043	12,153	12,703	24,856	3,003	89,607	92,610	21,420	123,089	144,509
Average 1986 admission rate	19.0	14.5	15.8	11.5	9.8	10.7	10.6	6.6	6.8	13.6	8.0	9.0
Average 1986 live discharge rate	14.3	12.1	12.6	8.7	8.0	8.4	3.9	9.7	9.5	9.6	9.9	9.9
Average 1986 death rate	0.8	1.7	1.5	0.8	1.7	1.2	0.0	1.4	1.4	0.7	1.5	1.4
Not ICF-MR Certified												
Total current residents	19,365	23,898	43,261	23,697	18,854	42,751	4,800	4,297	9,098	48,062	47,048	95,109
Average 1986 admission rate	21.5	20.4	20.9	12.8	10.3	11.6	15.9	8.9	12.5	17.1	15.4	16.2
Average 1986 live discharge rate	15.1	16.0	15.6	12.8	12.3	12.5	15.6	10.0	12.9	14.1	14.0	14.0
Average 1986 death rate	1.5	2.4	2.0	0.5	1.4	0.9	0.8	1.4	1.1	1.0	1.9	1.5
All Facilities												
Total current residents	25,629	44,676	70,304	36,050	31,556	67,607	7,803	93,904	101,707	69,481	170,137	239,619
Average 1986 admission rate	20.9	18.1	19.1	12.3	10.1	11.2	13.9	6.7	7.3	15.9	10.2	11.9
Average 1986 live discharge rate	14.9	14.4	14.6	11.1	10.8	11.0	10.9	9.7	9.8	12.6	11.1	11.5
Average 1986 death rate	1.3	2.1	1.8	0.6	1.5	1.0	0.5	1.4	1.3	0.9	1.6	1.4

Notes. Movement data are expressed as percent of set up beds. Table includes only facilities that were open all of 1986. It excludes a small number of facilities whose number of admissions or number of releases exceeded bed capacity. Certain facilities serve as diagnostic, placement and/or crisis centers. They receive and discharge large number of residents each year. These were excluded in order to reflect the movement status of persons in typical residential settings.

Resident Characteristics

The following tables present data on a range of diagnostic, medical and functional skills of residents of mental retardation facilities by ICF-MR certification status and facility size (15 and fewer/16 or more residents).

Level of Retardation/Type of Related Conditions

Table 14 presents the levels of retardation or types of related conditions for mental retardation facility residents reported to have mental retardation, epilepsy, cerebral palsy, autism, and/or spina bifida. Under "mentally retarded" are presented the estimated distribution of residents by level of retardation for individuals indicated to have mental retardation. Under "Related Conditions Only" are the estimates of prevalence of certain conditions among sample members who were indicated to have epilepsy, cerebral palsy, autism or spina bifida, but not mental retardation.

Persons with mental retardation. The NMES estimates indicated that 99% of the residents of mental retardation facilities who were reported to have mental retardation and/or related conditions, were reported to have mental retardation. This included an estimated 99.5% of residents of ICFs-MR. Essentially the same proportions were reported for large and small ICFs-MR and noncertified facilities. It is notable that of the persons indicated to have "mental retardation," 4% were classified as "borderline mentally retarded" or not technically within the range of measured intelligence (i.e., IQ) currently recognized as indicating mental retardation.

People with profound retardation were much more likely to reside in ICFs-MR than in non-ICFs-MR (49% vs. 14.5% of all residents). There were major differences between large ICFs-MR and large noncertified facilities in the proportion of their total populations reported to have different degrees of mental retardation. For example, among large ICFs-MR an estimated 54.5% of residents had profound mental retardation as compared with 17.4% of the residents of large noncertified facilities. An estimated 11.8% of large ICF-MR residents had borderline or mild mental retardation as compared with 35.0% of residents of large noncertified facilities. In contrast small ICFs-MR and small noncertified facilities were quite similar with respect to the distribution of their residents by level of mental retardation. Mild/moderate mental retardation had a much higher prevalence within noncertified residential facilities (64% of residents) than within ICFs-MR (30%).

People with conditions related to mental retardation (i.e., epilepsy, cerebral palsy, autism and/or spina bifida), but who were not also diagnosed as mentally retarded appeared to be rare among mental retardation facilities (an estimated less than 1%), but were slightly more common among the noncertified facilities (1.4% vs. 0.6% in ICFs-MR). Epilepsy was the most commonly reported condition of persons who did not have mental retardation, but made up only an estimated 0.6% of all residents with mental retardation and related conditions. Although residents were rarely reported to have related conditions only, Table 14 shows these conditions very commonly accompanied mental retardation among the residents of mental retardation facilities. The statistics on related conditions may also be underestimated somewhat because a diagnosis of mental retardation is frequently required for admission to these facilities.

Table 14: Percentage of Residents with Mental Retardation and Related Conditions in Mental Retardation Facilities by Level of Mental Retardation or Related Conditions and ICF-MR Certification Status

	ICF-MR Certification Status								
	ICF-MR Certified			Not Certified			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
Mentally Retarded									
Mild/Borderline	29.8	11.8	14.6	30.9	35.0	32.7	30.6	16.9	20.9
Moderate	27.7	13.4	15.6	33.2	28.3	31.0	31.4	16.7	21.0
Severe	25.4	19.7	20.5	22.6	17.5	20.3	23.5	19.2	20.5
Profound	16.5	54.5	48.8	12.1	17.4	14.5	13.6	46.3	36.7
Total	99.4	99.4	99.5	98.8	98.2	98.5	99.1	99.1	99.1
Related Conditions Only									
Epilepsy only	0.2	0.4	0.4	0.9	1.2	1.1	0.7	0.6	0.6
Cerebral palsy only	0.3	0.2	0.2	0.2	0.3	0.2	0.2	0.2	0.2
Autism only	0.0	0.0	0.0	0.1	0.0	0.0	0.1	0.0	0.0
Spina bifida only	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Multiple related conditions	0.0	0.0	0.0	0.0	0.2	0.1	0.0	0.0	0.0
Total	0.5	0.6	0.6	1.2	1.7	1.4	1.0	0.8	0.8

Notes. Statistics presented are proportion of total estimated population in each facility category indicated to have either mental retardation or a related condition by level of mental retardation or, if not indicated to have mental retardation, by a related condition. Columns may not add to 100% because of rounding. Statistics on residents with "related conditions only" are based only on 33 of the total 3,618 sample members.

Related Conditions by Level of Retardation

Table 15 presents estimates of the prevalence of conditions often associated with mental retardation among residents with different levels of mental retardation in ICFs-MR and noncertified residential facilities. Specific conditions included are epilepsy, cerebral palsy, autism, spina bifida and deafness or blindness.

Epilepsy. An estimated 29.6% of persons with mental retardation and related conditions residing in mental retardation facilities were reported to have epilepsy. This included 34.3% of ICF-MR residents and 21% of the residents of noncertified facilities. The presence of epilepsy was clearly associated with the level of mental retardation. About 15% of persons with mild mental retardation were reported to have epilepsy as compared with 43% of persons with profound mental retardation. This in itself accounts for most of the difference in prevalence of epilepsy between ICFs-MR and the noncertified facilities. But controlling for level of retardation, persons with epilepsy were still more likely to be residing in ICFs-MR than in noncertified facilities.

Cerebral palsy. An estimated 11.7% of persons with mental retardation and related conditions in mental retardation facilities were reported to have cerebral palsy. This included 13.5% of ICF-MR residents and 8.6% of residents of noncertified facilities. As with epilepsy, there was a clear association between cerebral palsy and level of mental retardation of residents. Cerebral palsy was noted in the medical records of an estimated 5.5% of the individuals with mild or borderline mental retardation, 6.4% of those with moderate mental retardation, 9.2% of those with severe mental retardation, and 19.5% of those with profound mental retardation. Again the higher prevalence of cerebral palsy among ICF-MR residents was substantially associated with the higher proportions of ICF-MR residents with severe impairments (see Table 15).

Autism. An estimated 3.5% of residents of mental retardation facilities had autism noted in their medical records. There was a significantly lower rate of reported autism among ICF-MR

residents than residents of noncertified facilities (2.5% vs. 5.4%). The prevalence of reported autism was highest among persons with severe mental retardation (5.6%). Estimated rates of autism among persons with moderate and profound mental retardation were 3.3% and 3.6%, respectively. An estimated 1.4% of individuals with mild or borderline retardation were reported to be autistic. An estimated 5.4% of the sample members who were indicated to have a related condition, but not to have mental retardation were reported to have autism. But this estimate was based on only 2 of 3,618 sample members, neither of whom resided in an ICF-MR.

Spina bifida. Spina bifida was estimated to be rare among the mental retardation facility populations. It was consistently reported to be below 1% for residents of both large and small ICFs-MR and noncertified facilities.

Blind or deaf. An estimated 7% of persons in mental retardation facilities were blind and/or deaf. About twice the proportion of persons in ICFs-MR were deaf or blind (8.8%) than in facilities that were not ICF-MR certified (4.3%). Again the difference was partially attributable to the association between these conditions and level of mental retardation; from 2.3% of persons with mild or borderline mental retardation to 13.8% of persons with profound retardation. Persons who were blind or deaf were more likely to reside in ICFs-MR of 16 or more residents (9.7%) than in noncertified facilities of 16 or more residents (5.2%), small ICFs-MR (3.9%) or other small facilities (3.6%).

There was a generally higher reported prevalence of multiple disabilities among persons with more severe degrees of mental retardation. However, the estimates obtained are likely to somewhat underestimate secondary disabilities among persons with severe cognitive impairments. Diagnosis of some secondary disabilities among persons with mental retardation (e.g., sensory impairments, psychiatric conditions) is at best difficult and quite likely to be done with different standards, different methods and different care across facilities.

Table 15: Percentage of Residents of Mental Retardation Facilities with Secondary and/or Related Conditions by Certification Status

	ICF-MR Certification Status								
	ICF-MR Certified			Not Certified			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
Mentally Retarded									
Borderline/Mild									
Epilepsy	18.9	15.7	16.7	14.0	13.8	13.9	15.6	14.8	15.2
Cerebral Palsy	5.2	7.9	7.1	6.0	2.4	4.2	5.7	5.3	5.5
Autism	0.0	1.1	0.8	1.1	3.0	2.0	0.7	2.0	1.4
Spina Bifida	0.0	1.3	0.9	0.4	0.0	0.2	0.3	0.7	0.5
Blind or Deaf	2.1	2.4	2.3	3.5	1.0	2.3	3.1	1.8	2.3
Moderate									
Epilepsy	22.7	26.7	25.6	15.1	21.5	17.7	17.3	24.7	21.5
Cerebral Palsy	5.7	7.3	6.9	5.9	5.9	5.9	5.9	6.8	6.4
Autism	3.1	2.8	2.9	1.4	7.2	3.8	1.9	4.5	3.3
Spina Bifida	1.1	1.5	1.4	0.4	0.0	0.2	0.8	1.0	0.8
Blind or Deaf	2.3	6.1	5.1	2.4	2.7	2.5	2.4	4.8	3.7
Severe									
Epilepsy	18.5	32.5	29.9	21.5	18.1	20.2	20.4	29.6	26.5
Cerebral Palsy	10.9	8.8	9.2	10.1	7.8	9.2	10.4	8.6	9.2
Autism	4.6	3.6	3.7	7.6	11.3	9.1	6.5	5.1	5.6
Spina Bifida	0.0	0.4	0.3	0.0	1.3	0.5	0.0	0.6	0.5
Blind or Deaf	3.0	4.3	4.1	4.5	5.8	5.0	4.0	4.6	4.4
Profound									
Epilepsy	27.6	44.6	43.3	29.2	48.4	39.6	28.6	44.9	43.2
Cerebral Palsy	15.3	19.7	19.0	19.7	25.1	22.5	13.9	20.2	19.5
Autism	2.1	2.5	2.4	6.1	15.0	10.9	4.5	3.5	3.6
Spina Bifida	0.0	0.5	0.5	1.5	0.0	0.7	0.9	0.5	0.5
Blind or Deaf	10.9	14.2	14.0	6.1	17.8	12.4	8.0	14.5	13.8
Related Conditions Only									
Epilepsy	33.0	72.1	66.6	78.1	80.3	79.3	70.1	75.9	74.1
Cerebral Palsy	67.0	27.9	33.2	14.4	19.7	17.3	23.7	24.1	24.0
Autism	0.0	0.0	0.0	7.5	10.6	9.2	6.2	5.0	5.4
Spina Bifida	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Blind or Deaf	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Total Residents with MR/RC									
Epilepsy	21.4	36.6	34.3	18.7	23.9	21.0	19.6	33.8	29.6
Cerebral Palsy	7.1	14.6	13.5	8.7	8.5	8.6	8.2	13.2	11.7
Autism	2.3	2.6	2.5	3.3	7.9	5.4	3.0	3.7	3.5
Spina Bifida	0.4	0.7	0.7	0.4	0.2	0.3	0.4	0.6	0.5
Blind or Deaf	3.9	9.7	8.8	3.6	5.2	4.3	3.7	8.7	7.2

Notes. Blindness is defined as inability, with use of corrective lenses, to recognize (because of visual acuity) familiar people at a distance of 2 or 3 feet. Deafness is defined as inability, with a hearing aid, to hear things said to an individual. Data on "related conditions only" are percent of residents reported not to have mental retardation within each of five types of related condition, who have the additional condition listed. Within groups, columns do not always total 100% because some residents with related conditions only had more than one listed. "Total residents with MR/RC" includes percentage of all residents with and without MR who have the listed conditions. Only 33 sample members (out of 3,618 total) were indicated to have "related conditions only."

Age Distribution of Residents

Table 16 presents estimates of the age distribution of persons with mental retardation and related conditions in ICF-MR certified and noncertified mental retardation facilities. Age distribution estimates are provided for all residents and separately for those with mild/moderate levels of mental retardation, those with severe/profound mental retardation, and those who only had related conditions. It should be noted that the exclusion of facilities with 1 or 2 residents and the general underrepresentation of other small "family foster care" facilities has likely caused some degree of underestimation of the proportion of children and youth in mental retardation facilities. This was due to the somewhat greater proportion of children and youth in small family foster care settings than in

other facilities (51% greater than all other facilities in the 1982 National Census of Residential Facilities, Lakin, Hill, & Bruininks, 1985). Based on statistics from the 1982 national census survey it would appear likely the proportion of children and youth in all residential facilities in 1987, including those of 1 and 2 residents, was greater than the 15.5% estimated in the NMES. Adjustments for the undercounted smaller facilities and the eliminated 1 and 2 person placements, based on 1982 National Census of Residential Facilities statistics, would suggest that children and youth (21 years and younger) made up about 18% (45,800) of the 1987 population of mental retardation facilities. These general limitations affect only the comparative statistics for smaller, noncertified facilities. As noted earlier the ICF-MR population estimates for both large and small facilities are very near the expected numbers as reported by the states.

Like earlier studies, the NMES showed clearly the overwhelmingly adult population in mental retardation facilities. It estimated that only 15.5% of persons with mental retardation and related conditions in mental retardation facilities were persons 21 years and younger. Even the adjusted estimate of 18% was considerably less than the 24.8% found in the 1982 national survey and 37.4% found in the 1977 National Census of Residential Facilities (Lakin, Hill, & Bruininks, 1985). ICF-MR facilities reported even smaller proportions of children and youth (13.7%) than the underestimated proportions reported in noncertified facilities (18.4%). The estimated 13.7% of ICF-MR residents being 21 years or younger represents a substantial decrease from the 22.6% in 1982 (Lakin, Hill, & Bruininks, 1985). The primary factor in this decrease is the rapidly decreasing number of children placed in large institutions, particularly public institutions, were the bulk of the ICF-MR capacity is concentrated. For example, between June 30, 1982 and 1987 the number of children and youth (21 years and younger) in state institutions decreased from 25,792 to 12,026 (White, Lakin, Hill, Wright, & Bruininks, 1988).

At the other end of the life span populations of mental retardation facilities are aging. According to NMES 5.5% of mental retardation facility residents were 65 years or older, including 5.8% of ICF-MR residents, and 4.8% of residents of noncertified facilities. In 1982 4.8% of all mental retardation facility residents were 63 or older, including 4.6% of all ICF-MR residents. In 1982 2.9% of small ICF-MR residents were 63 or older, by 1987 the estimated percentage of persons 65 or older in small ICFs-MR was only 3.5%, but still more than 2.9% reported in 1982. Persons 65 years and older made up 5.4% of residents with mental retardation and related conditions in noncertified facilities of 15 and fewer residents.

Resident age distributions were associated with level of retardation. Resident populations indicated to have mild or moderate levels of retardation contained lower proportions of children and youth than did the populations indicated to be severely or profoundly mentally retarded (12.2% vs. 17.9%). This was not only generally true, but was true within all facility sizes and types, including ICFs-MR and noncertified facilities. Conversely, higher proportions of older mental retardation facility residents were indicated to be mildly or moderately mentally retarded than were indicated to be severely or profoundly mentally retarded. Of all mildly/moderately retarded residents 9.4% were persons 55-64 years (9.3% in ICFs-MR), and 6.7% were persons 65 years or older (8.7% in ICFs-MR). Of all residents reported to be severely or profoundly retarded, only 6.3% were persons 55-64 years (6.7% in ICFs-MR), and 4.3% were 65 years or older (8.7% in ICFs-MR). These differences reflect the generally lower life expectancy of persons with severe and profound levels of mental retardation. But they are also affected by the increasing life expectancy in general for persons with mental retardation.

The concentration of the residential population in early adulthood (22 to 39 years) was notable. While only 30.8% of the U.S. population was between 22 and 39 years at the time of this study, an estimated 53.4% of the ICF-MR and 48.5% of the non-ICF-MR population in 1987 was in young adulthood. This bulge is affected somewhat by the increase of this age cohort in the general population, but is more directly the result of placement factors such as the relatively low representation of children and youth and older people in residential settings; because children and youth increasingly stay home until adulthood, and because older people with mental retardation and related conditions are often placed in nursing homes. In fact, according to the 1987 National Medical Expenditure Survey there were slightly more older people (65 or older) with mental retardation in nursing homes then in mental retardation facilities (about 15,500 versus 14,750).

Table 16: Age Distribution of Residents of Mental Retardation Facilities by Level of Retardation and Certification Status

	ICF-MR Certification Status								
	ICF-MR Certified			Not Certified			All Facilities		
Mentally Retarded	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
Borderline/Mild/Moderate									
0-14 years	1.5	3.6	3.0	3.1	4.0	3.5	2.6	3.8	3.3
15-21 years	9.1	6.6	7.3	7.9	13.0	10.1	8.2	9.4	8.9
22-39 years	49.2	50.2	49.9	52.3	44.1	48.6	51.4	47.6	49.2
40-54 years	27.3	19.5	21.8	22.5	23.8	23.1	23.9	21.4	22.5
55-64 years	7.8	9.8	9.3	8.8	10.4	9.5	8.5	10.1	9.4
65+ years	5.1	10.2	8.7	5.5	4.7	5.2	5.4	7.8	6.7
Severe/Profound									
0-14 years	2.7	4.7	4.5	9.1	9.9	9.5	6.7	5.3	5.6
15-21 years	8.1	10.9	10.7	16.0	20.8	18.1	13.0	12.1	12.3
22-39 years	60.3	54.6	55.1	49.4	49.4	49.4	53.5	54.0	53.9
40-54 years	19.2	18.4	18.5	17.2	12.2	15.0	18.0	17.7	17.8
55-64 years	8.4	6.6	6.7	4.0	5.3	4.5	5.6	6.4	6.3
65+ years	1.3	4.8	4.5	4.4	2.3	3.5	3.2	4.5	4.3
Related Conditions Only									
0-14 years	0.0	0.0	0.0	14.4	12.2	13.2	11.8	5.7	7.7
15-21 years	0.0	16.3	14.1	0.0	18.2	9.9	0.0	17.2	11.6
22-39 years	100.0	17.1	28.4	23.0	21.3	22.1	36.6	19.1	24.7
40-54 years	0.0	21.1	18.2	25.0	0.0	11.4	20.6	11.2	14.2
55-64 years	0.0	24.1	20.8	14.0	29.3	22.3	11.5	26.6	21.7
65+ years	0.0	21.4	18.5	23.6	18.9	21.1	19.4	20.3	20.0
Total MR and RC									
0-14 years	2.0	4.4	4.0	5.2	6.1	5.6	4.2	4.8	4.6
15-21 years	8.6	9.8	9.7	10.4	15.6	12.8	9.9	11.2	10.8
22-39 years	54.0	53.3	53.4	51.0	45.5	48.5	52.0	51.5	51.6
40-54 years	23.8	18.7	19.5	20.8	19.6	20.3	21.8	18.9	19.8
55-64 years	8.0	7.5	7.6	7.2	9.0	8.0	7.5	7.8	7.7
65+ years	3.5	6.3	5.8	5.4	4.2	4.8	4.8	5.8	5.5

Notes. Borderline/Mild/Moderate category includes 2.5% of estimated population which was reported to be mentally retarded, but whose level of retardation was not reported. The "related conditions only" category is based on only 33 of 3,618 total sample members.

Activities of Daily Living (ADLs)

Table 17 presents estimates of the proportion of residents of ICF-MR and noncertified facilities who were reported to be able to perform certain activities of daily living independently, with special equipment, only with assistance or supervision from other persons, or not at all.

Bathing/showering. An estimated 39.1% of persons with mental retardation and related conditions in mental retardation facilities were reported to be able to bathe or shower independently. Residents of ICFs-MR were reported to be much less likely to be able to bathe or shower independently than were the residents of noncertified facilities (28.4% vs. 57.7%). However, the size of this difference derived almost entirely from the residents of large ICFs-MR, only 23.8% of whom were reported to bathe or shower independently as compared with 56.9% of large noncertified facility residents. Among small ICFs-MR and small noncertified facilities, comparable proportions of residents were reported to be independent in bathing or showering (53.9% and 58.5%, respectively). Obviously a major factor in these statistics was the much higher frequency of substantial mental impairment among the large ICF-MR populations. To exemplify the effect of mental impairment, taking all sample members irrespective of placement, 79.5% of individuals reported to have mild mental retardation were reported to be able to bathe or shower independently as compared with 58.5% of persons with moderate mental retardation, 33.6% of people with severe mental retardation and 6.5% of persons with profound mental retardation.

Dressing. An estimated 45.6% of residents with mental retardation and related conditions were reported to be able to dress themselves without assistance or supervision. Rates of independent dressing were much lower in ICFs-MR than in noncertified facilities (36.2% versus 62.2%), but were not appreciably different between small ICFs-MR and small noncertified group homes (61.8% and 63.1%, respectively). The differences between large ICFs-MR and large noncertified facilities in the proportions of residents reported to be able to dress independently were very large (31.6% and 61.1%, respectively). Again differences in the ability of people with different degrees of cognitive impairment generally appear to be the primary factor in the differences between the different types of facilities. About 85% of persons with mild mental retardation were reported to be able to dress independently as compared with 68.3% of persons with moderate mental retardation, 44.5% of people with severe mental retardation, and 9.2% of persons with profound mental retardation.

Toileting. Over two-thirds of the residents with mental retardation and related conditions were reported to be able to use the toilet independently. The difference between ICFs-MR and noncertified facilities in the proportion of residents independent in toileting was also substantial (59.1% and 83.7%). However, no difference was noted between small ICFs-MR and small noncertified group homes (86.6% and 85.7%, respectively). An estimated 9.4% of residents were reported to not use the toilet at all. This included 12.5% of all ICF-MR residents and 14.6% of large ICF-MR residents. The proportion of residents reported to use the toilet independently ranged from 94.0% of residents with mild mental retardation, 88.9% of residents with moderate mental retardation and 76.6% of residents with severe mental retardation to 32.2% of residents with profound mental retardation.

Getting in and out of bed. An estimated 80.3% of residents with mental retardation and related conditions were reported to be able to get in and out of bed independently. While the proportion of all ICF-MR residents able to get out of bed independently was consistently lower than the proportion of noncertified facility residents (74.3% and 90.7%, respectively), a slightly higher proportion of residents of small ICFs-MR than residents of small noncertified group homes were reported to be able to get out of bed independently (96.6% and 92.7%, respectively). An estimated 4.6% of mental retardation facilities residents were reported to not even assist in getting themselves out of bed. This included 6.4% of large ICF-MR residents.

Feeding self. An estimated 77.2% of residents with mental retardation and related conditions were reported able to feed themselves without assistance. ICF-MR residents were considerably less often reported as independent than were noncertified facility residents (70.1% and 89.5%, respectively), although little difference was noted among residents of small ICFs-MR and small noncertified facilities (88.9% and 91.6%). An estimated 6.6% of mental retardation facility residents were reported to be unable to feed themselves even with the supervision or assistance of another person or equipment. This group included 9.2% of ICF-MR residents, almost all of whom were among the 10.8% of all large ICF-MR residents who were reported to be unable to feed themselves even with assistance.

Walking across room. Most residents (77.3%) with mental retardation and related conditions were reported to be able to walk across a room without physical assistance from other people or equipment. Another 1.2% were reported able to do so with the aid of equipment, but without assistance from another person. Comparable statistics for ICF-MR residents were 70.5% able to walk across a room completely without aid and another 1.4% with only the assistance of equipment. Residents of ICFs-MR were less likely to be ambulatory than residents of noncertified facilities (71.9% and 90.0%, respectively, without the assistance of another person). Again the differences were accounted for in the larger facilities, with small ICF-MR and small noncertified facility residents reported to be very similar in unassisted ambulation (93.9% and 91.2%, respectively). The proportion of ICF-MR residents reported to be unable to walk across the room even with the assistance of another person or equipment was 17.7%, including 20.7% of large ICF-MR residents. Small ICF-MR residents were less likely to be reported unable to walk across a room even with the assistance of equipment or another person than were residents of small noncertified facilities, but such levels of impairment were rare among both groups (1.3% and 3.6%, respectively).

Table 17: Percentage of Residents of Mental Retardation Facilities Performing Activities of Daily Living by Certification Status

Activity	ICF-MR Certification Status								
	ICF-MR Certified			Not Certified			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
Bathing or Showering									
No difficulty w/o help	53.9	23.8	28.4	58.5	56.9	57.7	57.0	31.5	39.1
Received assistance or supervision	46.0	76.2	71.6	41.5	43.1	42.3	43.0	68.5	60.9
Uses special equipment /no other assistance	0.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Dressing									
No difficulty w/o help	61.8	31.6	36.2	63.1	61.1	62.2	62.6	38.4	45.6
Received assistance or supervision	38.0	68.4	63.8	36.8	38.7	37.7	37.2	61.5	54.3
Uses special equipment /no other assistance	0.2	0.0	0.0	0.1	0.2	0.2	0.2	0.0	0.1
Using the Toilet									
No difficulty w/o help	86.6	54.2	59.1	85.7	81.2	83.7	86.0	60.4	68.1
Received assistance or supervision	12.2	31.1	28.2	11.2	13.4	12.1	11.5	27.0	22.4
Uses special equipment /no	0.2	0.1	0.1	0.4	0.0	0.2	0.4	0.1	0.2
other assistance	1.0	14.6	12.5	2.6	5.5	3.9	2.1	12.5	9.4
Did not do at all									
Getting In/Out of Bed									
No difficulty w/o help	96.6	70.3	74.3	92.7	88.2	90.7	94.0	74.4	80.3
Received assistance or supervision	2.6	23.3	20.2	5.7	7.0	6.3	4.7	19.5	15.1
Uses special equipment /no	0.2	0.0	0.0	0.0	0.2	0.1	0.0	0.1	0.1
other assistance	0.6	6.4	5.5	1.6	4.6	2.9	1.3	6.0	4.6
Did not do at all									
Feeding Self									
No difficulty w/o help	88.9	66.8	70.1	91.6	86.9	89.5	90.7	71.5	77.2
Received assistance or supervision	10.4	21.8	20.1	6.5	10.7	8.4	7.8	19.2	15.8
Uses special equipment /no	0.6	0.6	0.6	0.0	0.0	0.0	0.2	0.4	0.4
other assistance	0.2	10.8	9.2	1.9	2.4	2.1	1.3	8.9	6.6
Did not do at all									
Walking Across Room									
No difficulty w/o help	92.8	66.4	70.5	90.3	87.7	89.2	91.2	71.4	77.3
Received assistance or supervision	4.7	11.4	10.4	5.2	4.4	4.8	5.0	9.8	8.4
Uses special equipment /no	1.1	1.5	1.4	0.9	0.8	0.8	0.9	1.3	1.2
other assistance	1.3	20.7	17.7	3.6	7.1	5.2	2.9	17.5	13.2
Did not do at all									

Instrumental Activities of Daily Living (IADLs)

Table 18 presents estimates of the proportion of persons with mental retardation and related conditions in ICF-MR and noncertified mental retardation facilities reported to perform different instrumental activities of daily living independently (with or without difficulty), with help, or not at all.

Use of telephone. An estimated 25.8% of residents of mental retardation facilities were reported to use a telephone independently. Another 25.5% were reported to use a telephone with assistance. ICFs-MR had a much lower proportion of people reported to use the telephone independently than did noncertified facilities (15.6% and 41.6%, respectively), but no difference was found between small ICFs-MR and small noncertified facilities (38.7% and 38.5%, respectively). A much larger proportion of ICF-MR residents was reported to never use a telephone at all, even with "help of any kind," than residents of noncertified facilities (61.0% and 29.8%, respectively), the proportions were again essentially equal for small facilities with and without ICF-MR certification (28.8% and 27.7%, respectively). Major differences were found between large ICFs-MR and large noncertified facilities in both the percentages of residents using the telephone independently (11.4% and 44.9%, respectively) and the percentage not using the telephone at all (66.9% and 32.0%, respectively).

Managing money. An estimated 11.4% of persons with mental retardation and related conditions in ICF-MR and noncertified mental retardation facilities were reported to manage their money ("such as keeping track of expenses or paying bills") without assistance. Persons reported independent in managing their money included 6.5% of ICF-MR residents and 18.9% of residents of noncertified facilities. Only 5.4% of large ICF-MR facility residents were reported to independently manage their own money as compared with 19.5% of residents with mental retardation and related conditions in large noncertified facilities. Differences between small ICFs-MR and small noncertified facilities were small (12.5% and 18.4%, respectively). An estimated 60.8% of residents of both ICF-MR and noncertified facilities were reported to not participate in money management activities, even with assistance. ICF-MR residents were much less likely than noncertified facility residents to be involved in managing their own finances (70.8% and 45.5%, respectively), although no differences were noted between small ICFs-MR and small noncertified facilities (40.9% and 40.0%, respectively). The differences between large ICFs-MR and large noncertified facilities were substantial (76.2% and 51.2%, respectively).

Shopping for personal items. An estimated 15.6% of residents of both ICF-MR and noncertified mental retardation facilities were reported to "shop for personal items such as toilet items or medicines" without help. ICF-MR residents were considerably less likely to be independent in shopping for personal items than residents of noncertified facilities (8.7% and 26.4%, respectively). Among large facilities the differences between ICF-MR and noncertified facilities in the proportion of residents independently shopping for personal items was substantial (6.6% and 27.8%, respectively). Differences were much between small ICFs-MR and noncertified facilities (20.3% and 25.1%, respectively). Rates of independent or assisted involvement in shopping for personal items were also considerably lower in ICFs-MR than in noncertified facilities (42.7% and 72.4%, respectively). However, no differences were found between small ICFs-MR and small noncertified facilities in the proportion of residents involved in independent or assisted shopping for personal items (76.3% and 75.6%, respectively).

Use of personal or public transportation. A substantial minority (17.3%) of residents of ICF-MR and noncertified mental retardation facilities were reported to be independent in getting around the community by using personal or using public transportation. (Presumably few sample members used personal transportation "to get around the community," but the use of personal and public transportation was combined in the NMES instrument.) ICF-MR residents were much less likely to be able to use private or public transportation independently than residents of noncertified facilities (9.3% and 29.6%, respectively). Differences were substantial between large ICFs-MR and large

noncertified facilities (6.4% and 30.0%, respectively). Differences between small ICFs-MR and small noncertified facilities were minor (25.5% and 29.1%, respectively).

An estimated 37.8% of residents of both ICF-MR and noncertified mental retardation facilities were reported not to get around the community "at all," with or without assistance by using personal or public transportation. ICF-MR residents were much less likely than residents of noncertified facilities to use private or public transportation to get around town either independently or with help (48.0% and 22.0%, respectively). Differences between small ICFs-MR and noncertified facilities were negligible (16.8% and 18.4%, respectively); differences between large ICFs-MR and large noncertified facilities were notable (53.6% and 25.7%, respectively).

In a related analysis, notable differences were found among sizes and types of facilities in the extent to which assistance was provided to residents who were not independent to enable them to use private or public transportation to get around the community. For example, of the residents of small ICFs-MR who did not use private or public transportation independently (74.5% of all residents), 77.4% were provided assistance which permitted them to engage in the activity. Among small noncertified facility residents who were not independent, 74.0% received assistance; among nonindependent residents of large noncertified facilities 63.1% received assistance. In contrast of the large ICF-MR residents who did not perform the activity independently (93.6% of all residents), only 42.6% received assistance which permitted them to engage in the activity. Of course, most large ICF-MR residents live in public institutions which historically were constructed in geographically isolated settings and their location away from population centers may limit general access to public transportation.

Table 18: Percentage of Residents of Mental Retardation Facilities Performing Instrumental Activities of Daily Living by Certification Status

	ICF-MR Certification Status								
	ICF-MR Certified			Not Certified			All Facilities		
IADL	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
Using Telephone									
Independent	36.7	11.4	15.6	38.5	44.9	41.6	38.5	20.5	25.8
With help	32.6	21.7	23.4	33.8	23.1	28.6	33.5	22.1	25.5
Not at all	26.8	66.9	61.0	27.7	32.0	29.8	28.0	57.4	48.7
Managing Money									
Independent	12.5	5.4	6.5	18.4	19.5	18.9	16.6	9.3	11.4
With help	46.6	18.3	22.7	41.6	29.3	35.6	43.2	21.3	27.8
Not at all	40.9	76.2	70.8	40.0	51.2	45.5	40.3	69.4	60.8
Shopping for Personal Items									
Independent	20.3	6.6	8.7	25.1	27.8	26.4	23.6	12.3	15.6
With help	56.0	30.1	34.0	50.5	41.3	46.0	52.2	33.1	38.7
Not at all	23.7	63.4	57.3	24.4	30.9	27.6	24.2	54.6	45.6
Using Own or Public Transportation									
Independent	25.5	6.4	9.3	29.1	30.0	29.6	28.0	12.8	17.3
With help	57.7	39.9	42.7	52.5	44.2	48.5	54.1	41.1	44.9
Not at all	16.8	53.6	48.0	18.4	25.7	22.0	17.9	46.1	37.8

Disturbing Behavior and Moods

Table 19 presents estimates of the proportion of residents with mental retardation and related conditions exhibiting certain types of disturbing behavior "sometimes" or certain moods

"frequently." Estimates are presented for ICF-MR, noncertified and total facilities. The statistics on disturbing behavior included all members of the resident sample. Questions regarding "moods" in the National Medical Expenditure Survey were not asked of residents indicated to have profound mental retardation. Unfortunately, the absence of frequency and severity indicators for these behaviors and moods makes interpretation of the statistics somewhat difficult.

Gets upset/yells. About half (51%) of residents of ICF-MR and noncertified facilities were reported "sometimes" to get upset and yell. Small differences were noted between ICF-MR residents and those of noncertified facilities (53.6% versus 47.1%). Differences between large ICF-MR and large noncertified facilities were relatively small (54.0% and 45.4%, respectively). The estimates obtained for small ICF-MR and small noncertified facilities were not significantly different (51.7% and 48.7%, respectively).

Tries to hurt others. An estimated 28.5% of residents of ICF-MR and noncertified facilities were reported to sometimes attempt to hurt others physically. Again relatively consistent rates were reported across facility types and sizes. Somewhat higher proportions of ICF-MR residents were reported to be aggressive toward others than were residents of noncertified facilities (31.7% and 23.6%). An estimated 32.7% of large ICF-MR residents were reported to try to hurt others as compared with 22.5% of large noncertified facilities. Small ICFs-MR and small noncertified facilities had essentially equal proportions of their populations reported to try to hurt others (26.5% and 24.7%, respectively).

Tries to hurt self. An estimated 22.4% of all mental retardation facility residents were estimated to "sometimes" to try to hurt themselves. Self-injurious behavior was reported to be more prevalent in ICFs-MR (25.5%) than in noncertified facilities (17.6%). Differences were again greater between large ICFs-MR and large noncertified facilities (26.3% and 16.6%, respectively) than between small ICFs-MR and small noncertified facilities (21.1% and 18.6%, respectively).

Steals from others. An estimated 15.7% of residents of all mental retardation facilities were reported to steal from others on occasion. Reported rates showed considerable consistency across facility types and sizes. ICF-MR rates were 17%, as compared with 13.8% in noncertified facilities. Differences between large ICFs-MR and large noncertified facilities were small (17.2% and 12.9%, respectively). The estimates obtained for small ICFs-MR and small noncertified facilities (15.9% and 14.7%, respectively) were not significantly different.

Exposes self/Has problem sexual behavior. An estimated 12.4% of residents of ICF-MR and noncertified facilities were reported to expose themselves or to exhibit other problem sexual behavior. Slightly higher rates were reported in ICFs-MR than in noncertified facilities (13.7% and 10.5%), with only small differences between large ICFs-MR and noncertified facilities (14.0% and 8.6%, respectively). The estimates for small ICFs-MR and small noncertified facilities were essentially equal (11.7% and 12.3%, respectively).

Gets lost/wanders. An estimated 14.4% of persons with mental retardation and related conditions in ICFs-MR and noncertified residential facilities were reported to have problems with wandering and/or getting lost. Rates of reported problems of this type were quite consistent across the various types and sizes of facility. The reported rate for ICFs-MR was 16.1%; for noncertified facilities, it was 11.7%. Estimates for large ICFs-MR and large noncertified facilities

differed only slightly (16.5% and 11.4%, respectively). The rates reported by small ICFs-MR and small noncertified facilities were similar (14.1% and 12.1%, respectively).

Unable to avoid dangerous things/places. An estimated 23.6% of residents of all mental retardation facilities were judged by careproviders to present problems because of their being unable to avoid dangerous things and/or places. Reported rates were higher in ICFs-MR (28.3%) than in noncertified facilities (16.6%), particularly among the larger facilities (29.4% and 15.5%, respectively). Although there were differences between ICFs-MR and noncertified facilities, the degree of difference, which might be expected to be reflected in requirements for supervision, was not notably large, particularly given the substantial differences in staffing noted in Table 12.

Cries for no apparent reason. An estimated 12.5% of residents with mental retardation and related conditions were reported by careproviders to cry for long periods of time for no apparent reason. Differences in rates reported across facility types and sizes were relatively small, with reported rates for small ICFs-MR, large ICFs-MR and small noncertified facilities all being essentially equal (about 13%). Slightly lower rates were reported for large noncertified facilities (8.7%).

Moods

Frequently worried/apprehensive. An estimated 31.4% of persons with mild to severe mental retardation or related conditions in all mental retardation facilities were reported to be frequently worried or apprehensive. Reported rates were essentially equal across facility types and sizes.

Frequently unresponsive or withdrawn. An estimated 18.5% of persons with mild to severe mental retardation or related conditions in all mental retardation facilities were judged by their careproviders to be frequently unresponsive or withdrawn. The reported rates for ICFs-MR and noncertified facilities were essentially equal.

Frequently impatient or annoyed. An estimated 42.5% of persons with mild to severe mental retardation or related conditions in all mental retardation facilities were reported by their careproviders to be frequently impatient or annoyed. Reported rates were higher for ICFs-MR than noncertified facilities (47.0% and 38.3%, respectively). The same degree of difference was reported between large ICFs-MR and large noncertified facilities (47.7% and 39.8%, respectively), as between small ICFs-MR and small noncertified facilities (44.7% and 36.8%, respectively).

Frequently suspicious. An estimated 20.3% of persons with mild to severe mental retardation or related conditions in ICFs-MR and noncertified facilities were reported to frequently exhibit sense of suspicion. Reported rates did not differ significantly between types or sizes of facility.

Table 19: Percentage of Residents of Mental Retardation Facilities Exhibiting Disturbing Behavior or Moods by Facility Certification Status

	ICF-MR Certification Status								
	ICF-MR Certified			Not Certified			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
Disturbing Behavior									
Gets upset/yells	51.7	54.0	53.6	48.7	45.4	47.1	49.6	51.6	51.0
Tries to hurt others physically	26.5	32.7	31.7	24.7	22.5	23.6	25.2	29.9	28.5
Tries to hurt self physically	21.1	26.3	25.5	18.6	16.6	17.6	19.4	23.6	22.4
Steals from others	15.9	17.2	17.0	14.7	12.9	13.8	15.0	16.0	15.7
Exposes self/has problem sexual behavior	11.7	14.0	13.7	12.3	8.6	10.5	12.1	12.5	12.4
Gets lost/wanders	14.1	16.5	16.1	12.1	11.4	11.7	12.7	15.1	14.4
Unable to avoid dangerous things/places	21.9	29.4	28.3	17.6	15.5	16.6	18.9	25.6	23.6
Cries for long period for no apparent reason	12.5	13.7	13.6	13.0	8.7	10.9	12.9	12.3	12.5
Moods (excludes persons with profound mental retardation)									
Frequently worried/apprehensive	32.4	29.6	30.3	32.8	31.9	32.3	32.7	30.6	31.4
Frequently unresponsive/withdrawn	15.5	20.2	19.1	18.3	17.7	18.0	17.5	19.2	18.5
Frequently impatient/annoyed	44.7	47.7	47.0	36.8	39.8	38.3	39.1	44.5	42.5
Frequently suspicious	16.2	20.1	19.2	20.6	22.1	21.3	19.3	20.9	20.3

Notes. For "disturbing behavior" respondents were asked if the subjects "sometimes disturb [respondent] or others by . . ." (items in Table). For "moods" respondents were asked if the subjects were . . . .

Medical Conditions by Age

Table 20 presents estimates of the prevalence of certain medical conditions among residents of mental retardation facilities. Estimates are presented for ICF-MR certified facilities, noncertified facilities and the totals for both types of facility. Because of the association of these medical conditions with aging, separate estimates are presented for residents 54 years and younger and 55 years and older.

Comatose. None of the 3,618 members of the sample was reported to be comatose. Therefore, "comatose" was omitted from the following tables.

Circulatory conditions. Circulatory conditions, including present diagnoses of high blood pressure, hardening of arteries, or heart disease, or past occurrence of a stroke or heart attack, were reported for an estimated 11% of residents with mental retardation and related conditions in ICFs-MR and noncertified facilities (11% was the estimate for both types of facilities). This overall rate was considerably less than the rate of 20.8% obtained in the 1985 National Health Interview Survey for the general population. As expected, circulatory conditions were considerably more common among those 55 and older than among the younger residents (31.4% and 7.8%, respectively). Again estimates for the different facility types were similar, although there was a somewhat higher estimated prevalence of circulatory conditions among people 55 years and older in ICFs-MR (33.5%) than in noncertified facilities (27.4%). The main sources of the total difference was the difference between the two types of large facilities (33.3% and 21.2%, respectively). Because mental retardation facilities house a lower proportion of older persons than are found generally in the population (e.g., 5.5% of mental retardation facility residents compared to 11.5% of the general population are 65 years or older), a somewhat lower rate of circulatory disorders among mental retardation facility residents might be expected. Reported rates of circulatory conditions were also somewhat higher for persons in the smaller facilities. These differences were noted despite a slightly older population in the larger facilities. Whether they reflect actual differences in the prevalence of circulatory conditions or less effective identification of existing conditions in the larger facilities cannot be determined.

Arthritis or rheumatism. An estimated 4.6% of residents of all mental retardation facilities were reported to have arthritis or rheumatism. This compares with an estimated 12% of the total U.S. population reported to experience limitations from arthritis and rheumatism in the 1985 National Health Interview Survey. The magnitude of this difference cannot be explained by the somewhat younger population of mental retardation facilities than with the population as a whole. The estimated prevalence of arthritis and rheumatism among persons 55 and younger in mental retardation facilities (2.2%) was less than half of the estimated U.S. prevalence of arthritis and rheumatism in the U.S. population of persons under 45 years (5.4%). To some extent the differences in reported prevalence may have been affected by the type of responses gathered in the National Health Interview Survey (self-report with some "self-diagnosis" likely) and the NMES (reports of care providers). As in the general population, within the NMES sample arthritis and rheumatism were very highly related to age, 6 times as great among those 55 and older than among those 54 and younger. The estimated prevalence of arthritis and rheumatism among persons 55 years and older in mental retardation facilities (20%) was also lower than the estimated 25.5% reported for the general population 45 years and older in the National Health Interview Survey. Only small differences were noted in the prevalence of arthritis and rheumatism for different sizes and types of facilities, and these primarily among persons 55 years and older. Within the older age group, 25.3% of those in facilities of 15 and fewer residents were reported to have arthritis or rheumatism. This compared with 18% of older persons in facilities of 16 and more residents and only 15.3% in facilities of 76 or more residents. Differences between facilities with and without ICF-MR certification were not statistically significant.

Diabetes. The estimated prevalence of diabetes among residents of all mental retardation facilities was 2.0%. This compares with the National Health Interview Survey estimate of 2.6% of the U.S. population. There is a very high association of diabetes with aging (e.g., the rate among 18-44 year olds is one-fifth the rate among 45-64 years and one-tenth the rate of people over 65), and the difference in estimated prevalence between mental retardation facilities and the general population can be attributed largely to the smaller proportion of older people among the mental retardation facility residents than among the general population. Estimates of the prevalence of diabetes among ICF-MR and noncertified facilities were not statistically different.

Cancer. Cancer was rare among the residents of both ICF-MR and noncertified mental retardation facilities. The small number of individuals with cancer in the sample limited the precision of estimates across facility groups. The NMES estimated that 1.2% of residents in mental retardation facilities have some form of cancer. Differences between ICFs-MR and noncertified facilities were small and not statistically significant (1.3% and 1.0%, respectively). As expected the prevalence of cancer did vary by age groupings from .4% of persons 54 and younger to 6.8% of persons 55 and older.

Frequent constipation. Frequent constipation was reported as a problem affecting 20.9% of residents of all mental retardation facilities. Unlike the other medical conditions discussed above, frequent constipation was not associated with age. However, it was highly related to severity of mental impairment and more specifically associated with complications affecting amount of movement and the amount of upright positioning, as well as certain neuromuscular disorders and abdominal muscle weaknesses which can substantially contribute to constipation. Other contributors to constipation are relatively low fluid intake and general diet. The strong association between chronic constipation and severity of mental impairment was clearly demonstrated in the total NMES sample. It was reported for 10.1% of persons with mild mental retardation, 11.7% of persons with moderate

mental retardation, 15.5% of persons with severe mental retardation and 36.3% of persons with profound mental retardation. The association between severity of impairment and constipation was in turn coinvolved in the substantial differences in reported prevalence in chronic constipation in ICFs-MR and noncertified facilities. Frequent constipation was noted for 26.4% of ICF-MR and 11.1% noncertified facility residents. Reported rates of chronic constipation were 29.1% in large ICFs-MR and 10.6% in large noncertified facilities. Essentially the same rates were reported for small ICF-MR and small noncertified facilities.

Obesity. About 13.2% of residents in all mental retardation facilities were reported to be obese (defined rather subjectively as "being very overweight"). Slightly lower rates were reported for ICFs-MR than for noncertified facilities (12.1% and 15.2%, respectively). Smaller ICFs-MR reported considerably lower rates of obesity among their residents than smaller facilities without certification (10.6% and 17.3%). Reported rates of obesity were essentially the same in large ICFs-MR (12.4%) and large noncertified facilities (12.6%).

Table 20: Percentage of Residents of Mental Retardation Facilities with Selected Medical Conditions/Ailments by Facility Certification Status

	ICF-MR Certification Status								
	ICF-MR Certified			Not Certified			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
54 Years and Younger									
Circulatory conditions	8.5	6.9	7.1	9.7	8.0	8.9	9.3	7.2	7.8
Arthritis or Rheumatism	1.2	1.9	1.8	2.8	3.4	3.1	2.3	2.2	2.2
Diabetes	1.7	1.1	1.2	1.8	1.5	1.7	1.8	1.2	1.4
Cancer	0.8	0.2	0.3	0.4	0.7	0.5	0.5	0.3	0.4
Frequent constipation	11.5	29.4	26.6	11.0	10.7	10.9	11.2	25.1	20.9
Obesity	11.1	11.5	11.4	17.5	12.2	15.2	15.4	11.7	12.8
55 Years and Older									
Circulatory conditions	35.1	33.3	33.5	32.7	21.2	27.4	33.4	30.6	31.4
Arthritis or Rheumatism	28.3	19.5	20.7	23.9	12.8	18.8	25.3	18.0	20.0
Diabetes	4.9	6.8	6.5	3.8	8.5	6.0	4.2	7.2	6.3
Cancer	10.8	7.8	8.2	2.3	6.4	4.2	4.9	7.5	6.8
Frequent constipation	13.1	27.0	25.2	14.6	10.2	12.6	14.2	23.2	20.7
Obesity	6.7	18.0	16.5	15.4	14.9	15.2	12.7	17.3	16.0
All Residents									
Circulatory conditions	11.5	10.5	10.7	12.6	9.8	11.3	12.2	10.3	10.9
Arthritis or Rheumatism	4.3	4.3	4.3	5.5	4.6	5.1	5.1	4.4	4.6
Diabetes	2.1	1.9	1.9	2.0	2.4	2.2	2.0	2.0	2.0
Cancer	1.9	1.2	1.3	0.6	1.4	1.0	1.0	1.3	1.2
Frequent constipation	11.7	29.1	26.4	11.5	10.6	11.1	11.5	24.8	20.9
Obesity	10.6	12.4	12.1	17.3	12.6	15.2	15.1	12.4	13.2

Notes. Entries are percent of residents within each group who have selected medical conditions/ailments. Columns do not add up to 100% because some residents had more than one condition and some had none. "Circulatory conditions" includes present high blood pressure, hardening of the arteries or heart disease or past stroke or heart attack.

Use of Special Equipment and Devices

Table 21 presents estimates of the use of various kinds of special equipment and devices by residents of ICF-MR and noncertified residential facilities.

Corrective lenses. An estimated 30.7% of residents of mental retardation facilities wore corrective lenses in 1987. ICF-MR residents were considerably less likely than noncertified facility residents to wear lenses (23.5% and 41.6%). Large ICF-MR residents were much less likely to wear

corrective lenses (20.3%) than residents of large noncertified facilities (36.4%), small ICFs-MR (42.1%), or small noncertified facilities (46.7%).

Hearing aids. Hearing aids were worn by only an estimated 3.6% of residents of all mental retardation facilities. They were more often worn by residents of small facilities (6.4%) than large facilities (2.5%). There were no significant differences in hearing aid use between large ICFs-MR and large noncertified facilities (2.6% and 2.2%, respectively); nor between small ICFs-MR and small noncertified facilities (7.1% and 6.1%, respectively).

Special underwear or diapers. An estimated 15.5% of residents of mental retardation facilities wore special underwear or diapers, including 19.7% of ICF-MR residents and 9.2% of residents of noncertified facilities. Use was considerably higher in large ICFs-MR (22.3%) than in large noncertified facilities (11.1%), small ICFs-MR (4.6%), or small noncertified facilities (6.3%).

Wheelchair. An estimated 17.9% of all residents used wheelchairs. ICF-MR residents were more likely to use wheelchairs (24.5%) than residents of noncertified facilities (7.9%), but residents of small ICFs-MR were slightly less likely to use wheelchairs than residents of other small facilities (3.3% and 5.8%). Wheelchair use was highly associated with the most severe cognitive impairments. Among residents of all types of facilities, only 5% of persons with mild and moderate mental retardation used wheelchairs, as compared with 11.3% of persons with severe mental retardation and 39.1% of persons with profound mental retardation.

Walker, cane or crutches. An estimated 4.5% of residents of all mental retardation facilities used walkers, canes or crutches to aid them in walking. No differences were noted generally between ICFs-MR (4.6%) and noncertified facilities (4.4%), nor between the smaller ICF-MR and noncertified facilities (3.6% and 4.0%, respectively), nor the larger facilities (4.8% for both ICFs-MR and noncertified facilities).

Special dishes, cups, or utensils. An estimated 14.7% of persons with mental retardation and related conditions used adapted dishes, cups and/or utensils to aid them in feeding themselves. Persons in large facilities were considerably more likely than persons in small facilities to use adaptive utensils for eating (18.3% and 5.9%, respectively). Persons in large public institutions were most likely to use adaptive utensils for eating (24.0%). Use of adapted table settings was strongly associated with degree of cognitive impairment, therefore expectedly, residents of large ICFs-MR were considerably more likely to be provided with special dishes, cups, and utensils (22.4%) than residents of large noncertified facilities (7.5%), small ICFs-MR (7.7%), or small noncertified facilities (5.1%).

Mechanical devices for eating. Mechanical devises to assist residents with eating were rarely used in mental retardation facilities; only an estimated 1.1% of residents were provided with such equipment. The use of such equipment was largely reported for residents of large ICFs-MR (1.9%). Only an estimated 0.3% of residents of noncertified facilities used such equipment, although the reliability of this estimate is limited since it is based on only 4 sample members who used mechanical devices for eating.

Velcro fasteners or snaps for clothing. Velcro fasteners and snaps as an adaptation for persons who have difficulty with buttons and zippers were provided for an estimated 12.4% of residents of all mental retardation facilities. These adaptations were more likely to be used in large ICFs-MR

(17.3%) than in large noncertified facilities (6.2%), small ICFs-MR (7.0%) or small noncertified facilities (8.5%).

Symbol systems/communication boards. Symbol systems or communication boards were used as the primary means of communication by only 1.0% of residents of all mental retardation facilities. (Information was not gathered in the National Medical Expenditure Survey on the use of communication systems as supplements to primary use of spoken or signed language). Use of these alternative communication methods was low among all types and sizes of facilities, although slightly higher in large ICFs-MR (1.6%) than in large noncertified facilities (0.3%) or in small ICFs-MR and small noncertified facilities (both 0.4%).

Shower seats or tub stools. An estimated 14.7% of persons with mental retardation and related conditions in mental retardation facilities used seats or stools for bathing/showering. Such devices were more commonly used in large ICFs-MR (by 21.2% of residents) than in large noncertified facilities (9.7%), small ICFs-MR (5.4%) or small noncertified facilities (7.2%).

Portable toilets. Portable toilets were not frequently used by residents of mental retardation facilities (3.2%). They were more commonly used for residents of large ICFs-MR (5.1%) than in large noncertified facilities (1.9%), but more often in large noncertified facilities than in small facilities (0.7%).

Urinary catheter. Urinary catheters were rarely used by the residents of mental retardation facilities (1.0%). Estimated use of 1.4% in large ICFs-MR was only slightly higher than estimated use in noncertified facilities (0.5%) or small ICFs-MR (0.7%).

Colostomy bag. Colostomy bags were very rarely used by residents of mental retardation facilities. Only .3% of residents were estimated to use colostomy bags, with no significant differences reported by facility type or size.

Table 21: Percentage of Residents of Mental Retardation Facilities Using Various Types of Special Equipment and Devices by ICF-MR Certification Status

Equipment/Devices	ICF-MR Certification Status								
	ICF-MR Certified			Not Certified			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
Corrective lenses	42.1	20.3	23.5	48.7	36.4	41.6	45.2	24.8	30.7
Hearing aid	7.1	2.6	3.3	6.1	2.2	4.2	6.4	2.5	3.6
Special underwear or diapers	4.6	22.3	19.7	6.3	11.1	8.2	6.5	19.2	15.5
Wheelchair	3.3	28.1	24.5	5.8	10.0	7.9	5.0	23.1	17.9
Walker, cane or crutches	3.6	4.8	4.6	4.0	4.8	4.4	3.9	4.8	4.5
Special dishes, cups, utensils	7.7	22.4	20.2	5.1	7.5	6.3	5.9	16.3	14.7
Mechanical devices for eating	0.0	1.9	1.6	0.1	0.4	0.3	0.1	1.5	1.1
Velcro fasteners or snaps	7.0	17.3	15.8	8.5	6.2	7.4	8.0	14.2	12.4
Symbol system /communication board as primary means of communication	0.4	1.6	1.4	0.4	0.3	0.4	0.4	1.3	1.0
Shower seat or tub stool	5.4	21.2	18.8	7.2	9.7	8.4	6.6	18.0	14.7
Portable toilet	0.6	5.1	4.5	0.8	1.9	1.3	0.7	4.2	3.2
Urinary catheter	0.7	1.4	1.3	0.4	0.6	0.5	0.5	1.2	1.0
Colostomy bag	0.2	0.4	0.3	0.2	0.2	0.2	0.2	0.3	0.3

Employment Status and Wages

Table 22 presents estimates of the percentages of residents of ICF-MR and noncertified mental retardation facilities working for pay, their place of employment and their average hourly wages. Estimates include only residents 18 years or older.

Works for pay. An estimated 38.8% of persons with mental retardation and related conditions living in all mental retardation facilities were employed for pay. In general ICF-MR residents were much less likely to have paid work than residents of noncertified facilities (32.1% and 49.1%, respectively), although the proportions of small ICF-MR and small noncertified facility residents with paid employment were essentially the same (60.6% and 59.2%, respectively). An estimated 26.9% of large ICF-MR residents and 38.9% of large noncertified facility residents were reported to work for pay.

Location of employment. An estimated 26.3% of residents of all mental retardation facilities worked for pay off the grounds of the residential facility in which they lived. This represented 67.8% of all employed residents. Only an estimated 9.7% of large ICF-MR residents had a paid job away from the facility in which they lived. This compared with 26.8% of residents of large noncertified facilities, 52.6% of residents of small ICFs-MR and 56.5% of residents of small noncertified facilities. ICF-MR residents with paid jobs were also much less likely to have jobs away from the residence than were residents of noncertified facilities who had paid jobs (50.8% and 85.1%, respectively). Almost all the paid workers living in small ICFs-MR and small noncertified facilities, had jobs in which they worked away from the residential facilities (86.7% and 95.4%, respectively). Among the larger

facilities, residents of ICFs-MR who had paid jobs were much less likely to work away from the facility than paid workers living in large noncertified facilities (36.1% and 68.9%, respectively).

Type of employment. Sheltered workshops were the primary source of employment for residents of both ICF-MR and noncertified residential facilities. An estimated 29.8% of all mental retardation facility residents worked in sheltered workshops. This represented an estimated 76.8% of all residents working for pay. Although ICF-MR and noncertified facilities differed greatly in the proportion of their adult residents working for pay in any type of setting, the proportion of all workers who were employed in sheltered workshop settings was fairly consistent. An estimated 74.9% of paid workers living in ICFs-MR worked in sheltered employment settings, included 78.8% of those in small ICFs-MR and 73.4% of those in large ICFs-MR. Among noncertified facilities, 77.8% of all paid workers worked in sheltered employment settings, including 83.9% of paid workers living in small facilities and 68.5% of paid workers living in large facilities. Only 3.0% of all residents (7.7% of employed residents) were in supported work programs, and even fewer (1.4%) were in competitive employment settings. Residents of small ICFs-MR and noncertified residential facilities were more likely to be in supported or competitive employment (7.4%, and 5.9%) than were residents of large ICFs-MR (2.7%). Work for pay other than sheltered, supported or competitive employment, most frequently "in facility" work of various types, was reported for 4.8% of all residents, including 4.7% of ICF-MR residents and 5.1% noncertified facility residents.

Work with nonhandicapped people. A very small proportion of residents of ICF-MR and noncertified facilities were reported to work with persons who were not handicapped (7.1% of all residents and 18.3% of employed residents). Small ICFs-MR had the highest percentage of all residents (15.8%) and the highest proportion of employed residents (26.1%) in integrated employment settings. This rate of integration was considerably higher than 8.6% of all residents and the 14.4% of all employed residents of small noncertified facilities who were in integrated employment settings. On the other hand, large ICF-MR residents were less likely to have paid work in integrated settings than residents of large noncertified facilities (4.6% and 8.6%, respectively).

Hourly wages. The estimated average hourly wage for paid workers living in mental retardation facilities was $1.25 per hour. (The NMES did not request information on total hours worked so as to permit estimations of total income from work.) Average wages varied much more by the type of employment setting than by the residence in which workers lived. For example, sheltered workshop employees averaged $1.06 per hour as compared with $2.15 per hour for supported work participants and $3.87 per hour for persons in competitive employment. In contrast, ICF-MR residents with jobs averaged $1.16 per hour as compared with an average of $1.34 for residents of noncertified facilities. The highest average wages for employed workers were reported by small ICFs-MR ($1.62 per hour) and large noncertified facilities ($1.53). Large ICFs-MR reported an average hourly wage of $1.05 per hour for their working residents.

Table 22: Employment Status of Adult Residents of Mental Retardation Facilities by ICF-MR Certification Status

	ICF-MR Certification Status								
	ICF-MR Certified			Not Certified			All Facilities		
	15- res.	16+ res.	Total	15- res.	16+ res.	Total	15- res.	16+ res.	Total
Works for Pay									
In facility	8.0	17.2	15.8	2.7	12.1	7.3	4.4	15.8	12.5
Away from facility	52.6	9.7	16.3	56.5	26.8	41.8	55.2	14.4	26.3
Total	60.6	26.9	32.1	59.2	38.9	49.1	59.6	30.2	38.9
Type of Employment									
Sheltered employment	47.9	19.9	24.2	50.0	26.7	38.6	49.3	21.8	29.8
Supported/transitional employment	5.8	2.1	2.6	3.5	3.6	3.6	4.3	2.5	3.0
Competitive employment	1.6	0.6	0.8	1.7	2.9	2.3	1.7	1.2	1.4
Other	5.5	4.5	4.7	4.4	5.8	5.1	4.8	4.9	4.8
Total	60.8	27.1	32.3	59.6	39.0	49.6	60.1	30.4	38.9
Works with Non-handicapped People	15.8	4.6	6.3	8.6	8.1	8.4	10.9	5.6	7.1
Hourly Wages by Type									
Sheltered employment	1.12	0.97	1.03	1.03	0.99	1.01	1.06	0.98	1.02
Supported/transitional	1.96	1.70	1.80	2.46	2.84	2.63	2.21	2.09	2.15
Competitive employment	3.64	5.31	4.67	3.82	3.32	3.52	3.77	3.93	3.87
Other	2.45	0.53	0.90	1.53	2.30	1.94	1.86	1.12	1.35
Average hourly wage	1.62	1.05	1.16	1.23	1.53	1.34	1.29	1.21	1.25

Notes. Table includes only residents age 18 or older. Total by "Type of Employment" may not equal total "Works for Pay" because of varying item response rates.

Nursing Home Residents with Mental Retardation and Related Conditions

Table 23 presents estimates from the 1987 National Medical Expenditure Survey on the diagnostic characteristics and ages of persons with mental retardation and related conditions in nursing homes. In all there were a total of 204 sample members with mental retardation or related conditions among the 3,347 total sample members in the nursing home sample of the 1987 National Medical Expenditure Survey. These 204 persons yielded an estimated of 90,387 total persons with mental retardation and related conditions in nursing homes. These estimates have been broken down into 3 groups: 1) persons whose primary diagnosis in their medical records (i.e., the reason for placement) was mental retardation or a related condition; 2) persons whose primary diagnosis was mental illness, but who were also indicated to have mental retardation; and 3) persons whose primary diagnosis was a medical condition, but who were also indicated to have mental retardation or a related condition.

Level/Type of condition. Persons indicated to have mental retardation or a related condition as a primary diagnosis were estimated to number 57,849. About 78% of these persons were indicated to have mental retardation as a primary diagnosis. About 19% (10,900) were estimated to be people with a primary diagnosis of cerebral palsy. Although no level of mental retardation was specified in the records of 28% of the individuals with a primary diagnosis of mental retardation, the largest group by level of mental retardation was made up of persons with mild or "borderline" mental retardation (33.4% of persons with level of mental retardation indicated). About 24.6% of persons with level of mental retardation reported were indicated to be moderately retarded; 20.9% severely retarded, and 21.1% profoundly mentally retarded. There were an estimated 32,538 persons in nursing homes with primary diagnoses of mental illness or medical conditions who were reported also to have mental

retardation or a related condition. The majority of these persons for whom the level of mental retardation was known were reported to be mildly or borderline mentally retarded, including 86% of those with mental illness and 60.5% of those with medical conditions.

Age. Persons with mental retardation or a related condition living in nursing homes tended to be considerably older than the general population and much older than the population of persons in mental retardation facilities (see Table 17). Among persons with mental retardation or a related condition as a primary diagnosis the estimated median age was 56 years. Only an estimated 10.4% of nursing home residents with a primary diagnosis of mental retardation or a related condition were 21 years and younger. Of these 65.8% were reported to have profound mental retardation, 19.4% to have severe mental retardation, 7.4% were reported to have mild or moderate mental retardation and 7.4% had related conditions. On the other end of the age cycle there were an estimated 19,877 persons 65 years or older with a primary diagnosis of mental retardation or a related condition (34.4% of the total). The older group was much more likely to be mildly or moderately retarded than the younger groups. For example 31.1% of the 65 to 72 year olds with a reported level of retardation were reported to have mild or borderline mental retardation; 22% were reported to have moderate mental retardation; 23.3% had related conditions. Among persons with primary diagnoses of mental retardation or related conditions who were over 72 years, 39.4% of those with a specific level of retardation or related conditions indicated were mildly or borderline mentally retarded. An estimated 66.4% of persons with mental retardation or related conditions with primary diagnoses of mental illness were between 22 and 64 years. An estimated 83.3% of those with primary diagnoses of medical conditions were 55 years or older, with an estimated 47.3% reported to be 73 years and older.

Table 23: Number and Percentage of Nursing Home Residents with Primary Diagnoses of Mental Retardation (MR) or Related Conditions (RC) as Estimated in the 1987 National Medical Expenditure Survey

Characteristics	Primary Diagnosis of MR or RC		Primary Diagnosis of MI, also MR/RC		Primary Diagnosis of Medical Cond., also MR/RC		All Residents with MR/RC	
	Est. No.	Est. %	Est. No.	Est. %	Est. No.	Est. %	Est. No.	Est. %
CONDITION								
Mental Retardation								
Borderline/Mild	10,849	18.8	4,655	60.5	10,990	44.2	26,494	29.3
Moderate	7,998	13.9	759	9.9	4,022	16.2	12,779	14.1
Severe	6,794	11.7	0	0.9	0	0.0	6,794	7.5
Profound	6,858	11.9	0	0.0	2,113	8.5	8,971	9.9
Unspecified	12,762	22.1	2,275	29.6	6,680	26.9	21,717	24.0
Total MR	45,261	78.2	7,689	100.0	23,805	95.8	76,755	84.9
Related Conditions								
Cerebral Palsy	10,902	18.8	0	0.0	0	0.0	10,902	12.1
Others*	1,686	2.9	0	0.0	1,044	4.2	2,730	3.0
Total	12,588	21.8	0	0.0	1,044	4.2	13,632	15.1
Total MR/RC	57,849	100.0	7,689	100.0	24,849	100.0	90,387	100.0
AGE								
0-12 Years	2,797	4.8	0	0.0	1,170	4.7	3,967	4.4
13-21 Years	3,232	5.6	0	0.0	585	2.4	3,817	4.2
22-54 Years	20,473	35.4	4,366	56.8	2,398	9.7	27,237	30.1
55-64 Years	11,470	19.8	739	9.6	4,465	18.0	16,674	18.4
65-72 Years	13,950	24.1	670	8.7	4,473	18.0	19,093	21.1
73+ Years	5,927	10.2	1,914	24.9	11,758	47.3	19,599	21.7
Total All Ages	57,849	100.0	7,689	100.0	24,849	100.0	90,387	100.0

*Includes Autism, Spina Bifida, and a diagnosis of multiple handicaps, but with no indication of mental retardation.

Summary and Conclusions

This report has summarized basic utilization and resident characteristics data on Medicaid ICF-MR, waiver and nursing home program participants. No attempt was made to interview state officials about these programs as part of this study, although findings from such interviews are contained in a recent related report (Lakin et al., 1989).

One of the most striking findings of this study, although by no means a new phenomenon, was the high variability in states' ICF-MR utilization and in the associated federal reimbursements to states for services provided under the program. However, the variability noted was not found in all types of facilities. With respect to services offered in large state institutions, the consistently high rates of state utilization (93% nationally) suggest a high degree of agreement on the part of states that the program is appropriate and beneficial for public institutions. Similar conclusions are apparently being made about care in large nonstate facilities, in which the proportion of all residents living in ICF-MR units has increased from 23% in 1977 to 41% in 1982 to 70% in 1988.

The ICF-MR program is obviously judged as quite suitable for institutional care. But institutional care is decreasing, down from 147,463 to 137,610 residents of 16 or more person facilities in just the two years between June 30, 1986 and June 30, 1988. This trend will continue. It is the utilization of the ICF-MR option for community services which raises the primary questions about the program's future, both in terms of projected utilization of the current ICF-MR program and also the possible need for major reform of Medicaid in order to provide the most appropriate and cost-effective community services to persons with mental retardation and related conditions.

In 1988 the ICF-MR program remained primarily an institutional program. About 80% of ICF-MR service recipients lived in facilities of 16 or more residents. On the other hand, utilization statistics did indicate that nationally states continued to certify a substantial number of community-based facilities as ICFs-MR. Between 1986 and 1988 small ICFs-MR went from housing 20% of all small facility residents to 22%, an increase of about 8,100 total residents. However, this represented only 29% of the growth in community-based housing, as the number of residents of noncertified community facilities increased by about 19,500. These statistics reflect the ambivalence of states regarding the usefulness and appropriateness of the ICF-MR option for community settings. At present, despite very attractive federal cost-sharing of ICF-MR service expenditures, states vary considerably in their use of the ICF-MR option for community-based residences. At present only 14 states have certified the homes of at least 25% of their community facility residents for ICF-MR participation.

Data from the 1987 National Medical Expenditure Survey (NMES) also reflect this ambiguity among states in decisions about developing smaller community ICFs-MR. They suggest strongly that ICF-MR placements are more driven by policy decisions regarding financing strategies than by the establishment of the programmatic needs of potential residents. National estimates from NMES show small ICF-MR and small noncertified facility populations to be very similar. For example, 30% and 31% of residents, respectively, were estimated to have mild retardation, 16 and 12%, respectively, to have profound mental retardation. Among small ICF-MR populations an estimated 21% had epilepsy and 7% had cerebral palsy. Among small noncertified facility populations, estimates for epilepsy and cerebral palsy were 19% and 9%, respectively. Independently bathing was reported for 54% of small ICF-MR residents and 48% of small noncertified facility residents; independent dressing for 62% and 63%, respectively; independent toileting for 87% and 86%, respectively. There were no statistically

significant differences between the two populations on ambulatory abilities, behavior problems or medical conditions. What is more few differences were reported in the data on resident activities. For example, among small ICFs-MR 71% of residents were reported to use the telephone, with 33% receiving help to do so; among noncertified facilities, 72% of residents were reported to use the telephone, with 34% receiving help to do so. Among small ICFs-MR, 76% of residents were reported to shop for personal items, with 56% receiving help to do so, among noncertified 76% of residents were reported to shop for personal items, with 51% receiving help to do so. Statistics for managing money and using public transportation were also nearly identical.

Despite these similarities in resident characteristics and activities, the small ICFs-MR averaged 0.92 direct care staff members per resident, while the small noncertified facilities averaged 0.63 direct care staff members per resident. Staffing and other differences were in turn reflected in costs of care. While 68% of small ICF-MR residents were living in facilities that cost more than $55 per day, and 33% were in facilities that cost more than $80 a day, only 25% of residents of small noncertified facilities were living in places that cost more than $55 per day and 16% were in places that cost more than $80 a day. These differences are ones that states have identified in previous surveys as causing them to question whether sufficient benefit is derived from these different levels of expenditure (Lakin et al., 1989).

In light of interviews conducted with state mental retardation/developmental disabilities officials in 1988 (Lakin et al., 1989), it is particularly interesting to note that the number of people living in small ICFs-MR increased over the past two years more rapidly than did persons receiving Medicaid waiver services (an increase from 23,053 on June 30, 1986 to 28,689 on June 30, 1988). In those interviews, state officials were quite clear in their preference for the flexibility and individualizability of the waiver option for providing community services. However, most also noted that they experienced considerable difficulty in increasing the number of people to whom they were able to provide home and community based services because of utilization and cost restrictions in the Medicaid waiver regulations.

In general the past 2 years have brought considerably increased utilization of Medicaid ICF-MR and waiver services in community settings. From June 30, 1986 to June 30, 1988 the combined small ICF-MR and Medicaid recipients increased from 43,943 to 57,676 (31%). But despite this rapid increase, a very substantial majority of the new community service recipients were not provided services that benefitted from the favorable federal Medicaid cost share. Indeed, as costs of ICF-MR services continued to increase rapidly between 1982 and 1988 (55% per recipient as compared with a 14% increase in the Consumer Price Index), not only did the bulk of total ICF-MR expenditures continue to go to institutional care (86% in 1988), but so did over two-thirds of the increase in ICF-MR expenditures over the 6 year period. It is this continued drain of new funding as well as the continued lack of consistent federal support for community residential services that has brought such widespread attention to reform of Medicaid services for persons with mental retardation and related conditions. Such attention can only be expected to grow now that community facilities serve the majority of residents of all facilities for persons with mental retardation and related conditions.

The Medicaid Home and Community Quality Services Act, introduced in the U.S. Senate, and the Medicaid Community and Facility Habilitation Amendments, introduced in both Houses of Congress, have again focused attention on the ICF-MR program. Both bills would open up Title XIX federal program participation not just to people living in a single model of long-term care (ICF-MR), or to a restricted number of service recipients or expenditures as with the Medicaid waiver.

Both would essentially create new Medicaid programs for persons with mental retardation and related conditions who receive residential, habilitation, vocational, and support services provided as part of a comprehensive state plan, and monitored according to a comprehensive quality assurance system. Both bills respond to many criticisms of the current ICF-MR program. For example, they would not restrict community-based residential programs receiving reimbursement under Title XIX to a single set of residential program standards. States which develop community-based services such as foster care and semi-independent living, family supports, vocational programs and other "noninstitutional" services for their citizens with mental retardation and related conditions would be able to receive federal assistance in paying for them. Both proposed programs would likely over time reduce substantially the major disparities among states in the extent to which the federal government contributes to the costs of providing long-term care services for persons with mental retardation and related conditions. At the present time the most common federal support for community-based services still comes from the Supplemental Security Income (S.S.I.) and Social Security Disability Insurance (S.S.D.I.) programs, which provide barely ten dollars per day, as compared with an average of over $60 in daily federal contributions for people living in ICFs-MR.

Both proposals would also establish a role and commitment on the part of the federal government to stimulate minimal levels of quality assurance in community settings as well as institutions. As noted only 22% of the total population of community residential facilities for persons with mental retardation nationwide is in ICFs-MR. The remaining community residents, including those in Medicaid waiver supported programs, receive varying levels of protective oversight depending on the state and/or locality in which they live. The quality assurance requirements of both proposed Medicaid reform programs would represent a major departure from the present lack of federal attention to the quality of non-ICF-MR community services. Both bills would also represent a major departure from the present Medicaid waiver program in that federal financial participation in home and community-based services would not be linked to existing levels of federal funding of institutional care, although, quite likely, the demanding "maintenance of effort" language in the proposed "Medicaid Community and Facility Habilitation Amendments" would limit states' abilities to make major commitments to new programs. This in turn could considerably diminish the Bill's effectiveness in assisting states to deal with the sizable and growing waiting lists for community-based residential services, recently estimated at about 60,000 persons nationwide (Davis, 1987).

Generally speaking, good federal policy for residential and habilitation services should exhibit four characteristics. First, it should assure reasonable access to appropriate services to individuals who are eligible for and need long-term care and related services. Second, it should assure reasonable quality of services irrespective of the specific "placement" decisions that are made based on an individual's specific needs and circumstances. Third, it should promise cost-effective utilization of public resources. Fourth, it should stimulate the evolution of service options in socially desirable directions (i.e., living in natural communities, using services and institutions of those communities, having maximum opportunity for integration and social experiences with other citizens, having opportunities to exercise choice and independence, supporting families).

Clearly, the present Medicaid program is not meeting such standards. Access to services is far behind demand, with "openings" existing only in institutional settings which are underutilized because they are incongruent with prevailing standards of appropriate service. The federal government plays a significant role in the monitoring of the quality of services for only slightly more than half of the persons with mental retardation and related conditions in long-term care settings and much less for other types of services. Even where technically extended, the extensiveness and

appropriateness of federal oversight has been the subject of much doubt and controversy in recent years. The present long-term care system is extremely inefficient in its allocation of resources. The bulk of funding goes to facilities which offer less promise of exhibiting habilitative "productivity," but whose per person costs are growing far more rapidly than the demonstrably more effective community-based models of service (Larson & Lakin, 1989). It seems clear that the obvious inefficiencies of present policy competing against the tantalizing promise of generous federal cost sharing are together the primary reason states show such remarkable variation in their utilization of the ICF-MR option for community-based services. Finally, in no way can present policy be construed as reasonably impelling change in the direction of currently espoused social values.

Congress noted in the 1987 Developmental Disabilities Act that, "it is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens" (p. 3). It is difficult to see the present ICF-MR program as reflecting a serious commitment to advance this national interest. The current policy was developed in 1971 primarily to assure certain minimal standards of care and treatment to residents of large state institutions. Two decades later it seems essentially out of step with contemporary goals and standards for services to persons with mental retardation and related conditions, the vast majority of whom today receive those services while living in community-based residential settings or their own homes.

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